

ABSTRACT

Title of Document: **SIBLING RELATIONSHIPS IN FAMILIES OF
CHILDREN WITH
AUTISM SPECTRUM DISORDERS**

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Autism spectrum disorder (ASD) is one of the fastest growing disabilities in the United States. As the number of children diagnosed with ASD rises there is a parallel increase in families and siblings of children with ASD (F-ASD). There is a gap in the research (Meadan, Halle, & Ebata, 2010) on the interaction between children with ASD and other family members, especially siblings. In this study I explored sibling relationships in families of children with ASD with a focus on children of elementary to early middle-school age. Three research questions guided the inquiry: 1) What is the nature of sibling interactions in families of children with ASD, and do the individual characteristics of the child with and without ASD influence sibling relationships? 2) How do family attitudes and beliefs about ASD have an influence on sibling relationships? and 3) What factors contribute to parental decisions to access sibling support services? Sibling relationships in families of children with ASD were examined through observations, interviews, and focus groups. Siblings with and without ASD, parents, and clinical professionals

participated in the process in order to gain multiple perspectives. Consistent with qualitative methods (Miles & Huberman, 1994), a four-stage analytic process involving transcription of the data, coding and categorization, interpretation and identification of patterns and themes, and verification of the data was used to identify themes. Data analysis revealed one core theme and five subthemes. The findings of this study suggest that sibling relationships were bound by the way in which the ASD traits were seen in each child, the individual characteristics of each child, and the way in which the children and family perceived and understood their circumstances. The sibling relationships were, in many ways, similar to those between typical siblings but with an added layer of complexity related to the ASD. The findings are discussed with reference to current literature on sibling adjustment and relationships in families of children with disabilities. Implications for practice and future research are also discussed.

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AUTISM SPECTRUM DISORDERS

By

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Dedication

This dissertation is dedicated to the children with disabilities and special needs in this world who teach us how to love. You are the blessing to our lives.

“Doctors look at me and say I’m autistic, but my mummy holds me and says I’m perfect.”

-Unknown

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I would like to thank my family and friends who have provided endless support and encouragement throughout the years. Mom, thank you for your love and tireless prayers. You've supported me every step of the way. I couldn't have come this far without you.

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Chapter 1: Introduction

The presence of a child with disabilities in the family often presents an unexpected and significant change in family dynamics and interaction patterns. A main goal of the family is to have mutually satisfying and collaborative experiences that help to strengthen family bonds and equip members for successful social experiences in the larger society (Garner, Jones & Miner, 1994; Kitzman, Cohen, & Lockwood, 2002; MacDonald & Parke, 1984; McDowell & Parke, 2005). However, when there is a disability in the family, especially one in which the ability to form social relationships is hampered, this goal is challenged. Not only must the family reorganize its social norms, but also redefine familial expectations.

Census data from 2000 identifies 3.9 % of U.S. families in which one or more children had a disability (Wang, 2005), with 11% of all children between the ages of 6-14 identified as having a disability (U.S. Census Bureau News, 2007). Autism Spectrum Disorder (ASD) is one of the fastest growing disabilities in the United States. The incidence rate of children with ASD has increased sharply over the past 20 years from 2-5 per 10,000 (Kogan et al, 2009; Newschaffer et al, 2007) to 1 in 88 (Centers for Disease Control and Prevention, 2012). The findings from a recent study by Blumberg and colleagues (2013), exploring the number of children diagnosed with ASD, suggest that the numbers may now be as high as 1 in 50 children.

According to a 2007 National Children's Health Survey, 1 percent of the population of children in the U.S. ages 3-17 have an autism spectrum disorder (Kogan, Blumberg, Schieve, Boyle, Perrin, Ghandour, R.M., et al, 2009). The US Department of Education (2003) has indicated an estimated 10-17% annual growth rate in the number of children diagnosed with ASD.

The rise in children with ASD inherently means that there is a parallel increase in families and siblings of children with ASD. As public awareness of this phenomenon has become more

prevalent, a growth in family support services has emerged for these families. These services include intervention services for the child with ASD (Maryland State Department of Education, 2003), parent support venues (Autism Society of America, 2013; Autism Speaks, 2013), and also sibling support services (Sibling Support Project, 2013). This evolution in ASD awareness and support underscores the significance of this disorder to family functioning.

Autism Spectrum Disorders

Specific characteristics of ASD influence the interaction quality within family relationships. Autism¹, Asperger's Syndrome and Pervasive Developmental Disorder (PDD-NOS)² make up a triad of disorders that fall under the umbrella term, *Autism Spectrum Disorders* (ASD).³⁴ ASD has at its core a social-communication deficit, in which there is a spectrum of functioning related to communication ability, social understanding, and behavioral adaptability and flexibility (Stein, Klin, & Miller, 2004).

Although in earlier theories ASD was attributed to impaired maternal-child relationships, the etiology of ASD has been found to be neurological and identifiable before the age of 3 (Landa, 2008; Landa, Holman, & Garrett-Mayer, 2007). The distinction between autism, Asperger's Syndrome and PDD-NOS is controversial; however, one main differentiating feature is that children with autism typically have a delay in language development which is not the case with children with

¹ There are five diagnoses that fall under a larger diagnostic umbrella of Pervasive Developmental Disorders: Autism, Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (American Psychiatric Association, 2000).

² The diagnosis of PDD-NOS is typically utilized when there is significant and pervasive impairment in social-communication ability, but the criteria for a specific Pervasive Developmental Disorder has not been established (American Psychiatric Association, 2000). Due to the spectrum of functioning within ASD, a modification to an original diagnosis of PDD-NOS to either autism or Asperger's Syndrome may occur as the child develops.

³ The specific diagnosis of autism will be denoted by a lowercase "a" to distinguish it from the wider category of ASD. Literature discussing the ASD triad often has the term Autism to refer to the triad of disorders that make up ASD.

⁴ New diagnostic labels are expected to be utilized for children with an autism spectrum disorder. The new DSM V (expected release date of 2013) will no longer utilize autism, Asperger's Syndrome or PDD-NOS. Children will now be diagnosed with "autism spectrum disorder." However, all children diagnosed prior to 2013 will continue to hold their current diagnosis (autism, Asperger's Syndrome, or PDD-NOS).

Asperger's Syndrome (American Psychological Association, 2000). ASD's impact on an individual can range from mild (Asperger's Syndrome) to severe (autism). Hallmark symptoms of ASD include impairment in ability to read social cues, non-verbal communication (such as eye contact and facial expressions), emotion regulation, emotion identification and expression, perspective-taking, turn-taking, and reciprocal interactions (APA, 2000; Attwood, 2007; Klin, Volkmar, & Sparrow, 2000). Children with ASD often have cognitive impairment, delays in speech development (autism), and impairments in the use and understanding of the pragmatics of language for social interaction. Characteristics of the language and communication deficits seen in children with ASD often include unusual speech patterns such as: echolalia (automatic repetition of vocalizations made by another person), speaking too loudly/softly or too fast/slow, monotone cadence of speech, repetitive speech (repeating of certain words or phrases—not necessarily of another person's), or even an absence of verbalizations (APA, 2000; CDC, 2012). Additional communication challenges that may exist include a lack of eye contact when speaking with the partner or a lack of comprehension of what is being said or received. Communication exchanges may lack reciprocity, presenting as monologues versus mutual involvement in the conversation. These children also tend to have difficulty with adjusting their conversational style, tone and language based on audience. It is important to understand that while there is a common attribute of social-communication difficulties in ASD, there is a range of ability in cognitive and other skills. For example, some children with autism may have lower IQ scores and verbal abilities, but have extraordinary musical, artistic or even savant abilities. Similarly, there are a percentage of children with Asperger's Syndrome who have superior intelligence, noted by IQ scores in the genius level.

Behavioral manifestations associated with ASD include repetitive and stereotyped behaviors, rigidity in thinking, self-stimulating behaviors (such as hand flapping or spinning),

perseverative or obsessive behaviors and intense interest in objects/topics often not shared by age-matched peers. An impaired theory of mind (ToM) has been offered as one mechanism underlying of the key debilitating aspects of ASD (Baron-Cohen, 2001). Theory of Mind is a construct related to attributing mental states of others (e.g., emotions, intents, thoughts, motivations, desires), making inferences, and perspective taking (Baron-Cohen, 2001; Baron-Cohen, Leslie, & Frith, 1985; Frith, Happe, & Siddons, 1994; Hutchins, Bonazinga, Prelock & Taylor, 2008). Children with ASD have particular deficits in this area, sometimes called “mind-blindness,” which presents significant challenges to the development of social connections and friendships. Even the basic initiating, facilitating, terminating, or joining into a conversation are taxing for children with ASD. In part, this challenge is due to difficulties with demonstrating, identifying, and recognizing basic emotions, especially those that are more subtle in their emotional display.

The characteristics just described are not exhaustive and all traits may not be seen in every child. ASD uniquely contributes to family functioning in that it can change family dynamics, some of which may cause stress to the system. Moreover, the deficits associated with ASD can significantly impair bi-directional family engagement.

Overview of the Literature

The extant literature on family dynamics and functioning in families of children with disabilities is relatively large. However, what is known on this topic specific to *families of children with ASD* (F-ASD) is small. Different theories have been identified within which to understand family functioning. Applying a family systems perspective (Bowen 1978; Minuchin, 1974), a framework derived from the Transactional Model (Sameroff, 2009) and the Circumplex Model of Marital and Family Systems (Olson, 2000) is a context within which to situate this problem.

Although researchers have begun to look at a few family factors, the focus of research has primarily been on family functioning and the impact of intervention programs (Grindle, Kovshoff, Hastings & Remington, 2009; National Institute for Child Health and Human Development, 2001; Solish & Perry, 2008; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). In addition, a burgeoning interest in a potential genetic basis for ASD has warranted a great deal of attention (Cassel et al., 2007; Gardener, Spiegelman, & Buka, 2009, 2011; Landa & Garrett-Mayer, 2006; Rutter, 2000; Wassink et al., 2004; Yirmiya et al., 2006; Zwaigenbaum et al., 2005). A fundamental gap in the current literature on ASD is the examination of how the core traits of the disorder influence the various combinations of family relationships (i.e., parent-child, sibling, parental, etc.).⁵

The myriad of factors related to family functioning and dynamics in F-ASD have started to be examined in the literature, including the combined effects of ASD on family stress, sibling adjustment, and overall family functioning (Floyd & Zmish, 1991; Hutton & Caron, 2005; Rao & Biedel, 2009; Trute, 1990). The research that has been done on ASD and the family, especially parental stress, has only peripherally focused on the bi-directional influence each family member has on one another within the family system (e.g., Gray, 2002; Kasari & Sigman, 1997). A recent review of the literature on F-ASD and stress revealed such a gap with respect to the lack of research on the transactional processes that occur between the family and the child with ASD (Meadan, Halle, & Ebata, 2010).

As an integral part of the family unit, the quality, role, and mutual impact of the sibling relationship to the family's life course has been an underrepresented topic in the disability literature at large, and even more so with the ASD population (Meadan, Stoner, & Angell, 2010). The sibling relationship is multifaceted and influences and is influenced by various aspects of the family

⁵ In addition to the typical caregivers, it is not uncommon for ASD families to have additional (in-home) therapists working with children for extended periods of time during the week. These relationships, however, are not the focus of this study.

climate. The nature of the sibling relationship, including how well siblings understand each other and coexist, is largely shaped by individual child characteristics (e.g., gender, age, birth order, temperament), as well as each child's response to issues specific to the sibling system and the larger family system (Ainsworth, 1978; McHale, Updegraff, Helms-Erikson & Crouder, 2001; Yu & Gamble, 2008). The nature and experience of the sibling relationship in childhood may be even more critical for children in F-ASD, especially as they mature. The non-ASD child may come to serve multiple roles for his/her sibling ranging from playmate in early childhood to confidant as teenagers to caregiver in adulthood. Thus, the bonds between siblings in F-ASD may be especially shaped by their unique experiences. Likewise, the quality of these changing relationships throughout the life-course may be greatly influenced by the foundation set in childhood. The prominence and scope of influence the sibling relationship has on the immediate individual and family experience is often underestimated (Gray, 2002; Hutton & Caron, 2005). Although researchers have begun to examine ASD sibling relationships, a large portion of the research has focused on the adjustment of the typically developing sibling (Benderix & Sivberg, 2007; Giallo & Gavidia-Payne, 2006; Mascha & Boucher, 2006; Petalas et al, 2009; Van Piper, 2000) and not on the experience of the child with disabilities. The available research, however, has provided a foundation for understanding the ways in which having a child with a disability in the family can alter how: 1) parents interact with their children; 2) parents impart norms, beliefs, and values; and 3) the family functions as a unit (Abidin, 1995; Bouma & Schweitzer, 1990; Noh, Dumas, Wolf, & Fisman, 1989; Sivberg, 2002; Smith, Oliver, & Innocenti, 2001).

Statement of the Problem

The increase in children with ASD, the nature of the disorder, and its potential impact on family relationships, makes it imperative to understand what is happening in the lives of these

children and their families. Research on ASD and advances in identifying the disorder have provided opportunities for more children to be diagnosed at earlier ages and for other connections to ASD to be found (i.e., familial/genetic contributions) (Landa, 2008). This has profound implications for the family.

On the micro level, family interactions and bonding are shaped by the ability of its members to effectively communicate and relate with one another. Sibling relationships may be at particular risk when one or more children have significant social-communication impairments, as with ASD. Sibling relationships are fundamental to the social development of all children; perhaps even more so for children with ASD. Noted as one of the most influential and long lasting of family relationships (Furman & Buhrmester, 1985), issues of sibling dynamics and relationship quality takes on heightened application when one in the pair (or larger sibling group) has ASD. Amongst several unique issues related to siblings in families of children with disabilities, the sibling relationship through the lifespan is especially important to consider in F-ASD. Long-term dynamics are particularly important in a situation where a disability may have unique implications for the adult sibling pair. For instance, it is not uncommon for there to be a shift in the roles between siblings in adulthood, with the typical sibling being called upon to assume more caretaking responsibilities. With ASD research still in its infancy, additional foundational research is needed to better understand how various family factors, in concert with ASD, shape the quality of these special sibling relationships. An examination of early sibling relationships is needed to enhance our understanding of the course of sibling relationships through the lifespan. This knowledge can help inform the research community to the need for and the influence of family support services to specific family relationships and milestones.

In this study, I examined sibling relationships and interactions in families of children with ASD (F-ASD). Using a qualitative approach, detailed observations and interviews were conducted to provide a rich data source for exploring this issue. Since little is known about what F-ASD seek out for support, interviews and questionnaires were also utilized to explore how families utilize sibling support services in fostering family relationships.

Research questions

- 1) What is the nature of sibling interactions in families of young children with ASD?**
 - a. How do the individual characteristics of children with and without ASD influence their sibling relationship?
 - b. How does parental assistance, guidance, scaffolding, and communication influence sibling interactions?
- 2) How do family attitudes and beliefs about ASD have an influence on sibling relationships?**
 - a. How do typically developing siblings learn about ASD within the context of the family?
 - b. How do siblings with ASD learn about and understand their disorder especially within the context of the family and sibling relationships
- 3) What factors contribute to parental decisions to access sibling support services?**
 - a. How do families utilize support services for siblings in fostering family relationships?
 - b. What significance do sibling support services have for parents and children?

Definition of Terms and Main Constructs

As noted earlier in this chapter, *Autism Spectrum Disorder (ASD)* is a broad term used to describe children who fall within one of three specific diagnoses: autism, Asperger's Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified.⁶ For the purpose of this research, the "high functioning" end of the ASD continuum will be the focus. "*High functioning*"

⁶ It is important to note that in May 2013 the DSM V will come out. It is suspected that the diagnostic categories of autism, Asperger's Syndrome and PDD NOS will end and all of these children will now be classified as having Autism Spectrum Disorder.

is defined as a child having age appropriate verbal ability (although not necessarily age appropriate pragmatic language abilities) and a cognitive/intellectual ability at least within the average range.

Reviewing the literature shows, with slight variation, definitions of the terms *dynamics* and *functioning* to refer to the family with regards to: 1) psychological well-being; 2) adjustment; 3) adaptation ; 4) interaction style; and 5) quality of relationships (Turnbull, Summers, Lee, & Kyzar, 2007; Ylvén, Björck-Åkesson, & Granlund, 2006). In this research, I will use these terms interchangeably to describe the way in which the system/ family operates as a whole and its capacity to meet the needs of its members. Within the context of the research questions, I explored sibling relationships with special consideration to level of involvement, type of involvement, warmth/ closeness between siblings, and communication style.

Chapter 2: Literature Review

In this chapter I examine the research on sibling and family dynamics in families of children with ASD. The chapter will be organized around the following: 1) a theoretical framework for considering sibling relationships; and 2) a review of the current literature on ASD and sibling and other family interactions.

A large research literature exists on the impact of disabilities on a variety of child and family outcomes. For example, investigators have examined the family's influence on child outcomes, such as social competence and academic performance (Jones & Prinz, 2005; Parker, Boak, Griffin, Ripple & Peay, 1999; Pelligrini, 1985), and siblings' adjustment to a disability in the family (Giallo & Gavidia-Payne, 2006; Nixon & Cummings, 1999). Families of children with disabilities, including ASD, are potentially at greater risk for negative family outcomes such as increased stress (Abbeduto et al., 2004; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005), lower levels of family satisfaction and well-being (Hastings, 2003a; Rivers & Stoneman, 2003), and increased mental health problems (Bromley, Hare, Davison, & Emerson, 2004; Keller & Honig, 2004; Weiss, 2000). The results of these studies suggest that positive family functioning is at risk in these families.

Family Dynamics and Functioning: Theoretical and Conceptual Framework

A family's social system is defined by the social relationships formed between family members and the manner in which they relate to one another (Bowen, 1978; Minuchin, 1974, 1985). Broadly speaking, family functioning is dependent on the patterns that organize family processes within a particular context or family situation. Various relationships (e.g., sibling, parent-child) within the larger family system are established, each with its own set of norms for engagement (Minuchin, 1974, 1985). The impact of a child's disability is experienced by all family members and influences the multiple layers of family dynamics, relationships, and overall functioning.

Researchers have often approached the study of families of children with disabilities from an “outside-in” perspective, in which the child’s environment influences his developmental outcomes (Bronfenbrenner, 1986; Bronfenbrenner & Ceci, 1994). It is equally important to consider the mutual impact the child (with ASD) has on his ecological systems. This added “inside-out” conceptual framework creates an overlapping system of influence which helps to illustrate the bi-directional/transactional experience that occurs within the family (see Figure 1). A bi-directional point of view would suggest that family functioning and child outcomes have a mutually influential impact. The conceptual framework for this study is based on the premise that there is a system of reciprocal relationships within which a child with ASD influences and is influenced by the broader systems of the family.

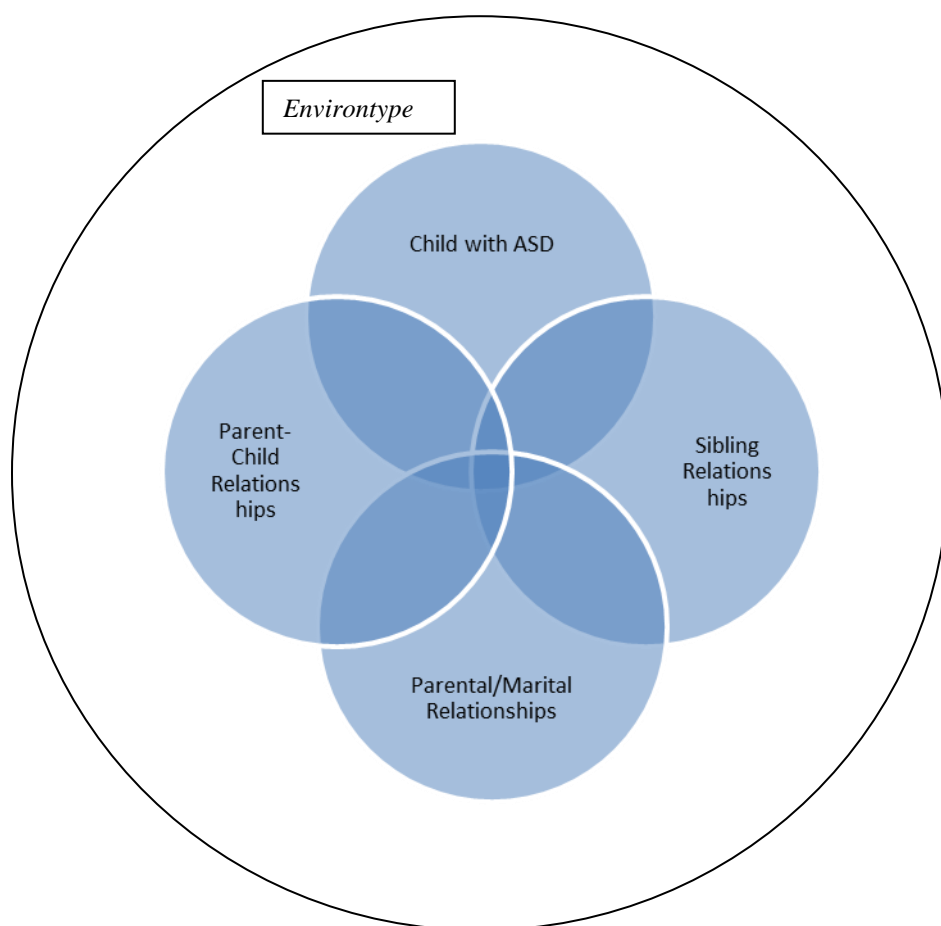


Figure 1. Conceptual model: An elaboration of the transactional perspective.

Understanding the effects of ASD on family dynamics requires consideration of the social environment in which ASD occurs (Bronfenbrenner & Ceci, 1994; Sameroff, 1995; Sameroff, 2009). The familial social environment is created through the interaction patterns of the family, including the way in which family members engage with and respond to all children, including the child with ASD. Thus, the overall family social environment emerges from the intersection of interactions between the multiple family subsystems.

The Transactional Model of Development (Sameroff, 2009) and the Circumplex Model of Marital and Family Systems (Olson, 2000) are two theoretical perspectives that are particularly relevant to consider regarding families of children with ASD. The Transactional Model may be used to address the mutual impact ASD has on the child and his environment, whereas the Circumplex Model touches on the relational nuances in the family. Considering them together may provide a way to understand the range of issues under consideration in this study.

Transactional Model of Development

The transactional model, developed by Arnold Sameroff (Sameroff, 1995; Sameroff, 2009; Sameroff & Fiese, 2000), provides a structure and perspective for understanding development at the individual and family level, particularly for children with disabilities. A fundamental assertion of the model is that development is dynamic and influenced by the mutual interaction of the individual and his experience with the environment, "...core to the transactional model is the analytic emphasis placed on the bidirectional, interdependent effects of the child and environment" (Sameroff, 2009, p. 6). A main tenet of the transactional model is that an individual's development is best understood in context of his environment, in which there are multiple, interactive systems. Moreover, the interactions of the members in those systems are dynamic and influenced by the

quality of their relationships with each other. In the family, an evolving set of “interaction maps” is created based on the transactions that occur within the family environment.

There are three contextual factors emphasized in the transactional model in relation to individual development. Applying them to ASD, they are as follows: 1) genotype (genetic inheritance: the disability); 2) phenotype (specific behaviors related to the person or disability) and 3) environtype (external experiences: cultural, family, and individual code beliefs; values and personalities of family members; family interaction; family understanding and acceptance of child behavior/disability). These contextual factors provide a framework in which to understand the mutually influential interactions between the child and the environment. Returning to the “inside-out” perspective, the unique characteristics of the child (genotype and phenotype), contribute to the way in which the environment influences the child and he, in turn, engages with the environment.

The envirotype is made up of various subsystems that transact with the child and also with one another (Sameroff, 2009). These overlapping subsystems include the family, school, and community. The dynamic exchanges between the subsystems influence the developmental trajectory of the family as a whole. Other ecological factors such as social support, socioeconomic or financial resources, and family mental health also contribute to family social relationships (and can serve as either a protective or a risk factor) and are part of the envirotype. Although this theory is meaningful for understanding how children with ASD affect, and are affected by their families, it does not offer a conceptualization of the mechanisms by which this occurs, and the processes that define relationships in families of these children. The Circumplex Model may provide a way to consider the dynamics of family interaction in a more focused way.

Family Systems: Circumplex Model of Marital and Family Systems

The Circumplex Model of Marital and Family Systems, proposed by Olson (2000), is an extension of the family systems perspective. Family system theorists (e.g., Bowen, 1978; Epstein, Baldwin, & Bishop, 1983; Minuchin, 1974) view the family as a system comprised of interconnected relationships, with a set of common patterns, norms, behaviors, and goals. Similarly, Olson posits that the family is a unit whose functioning is dependent on each of its members. Furthermore, the quality of the relationships is deeply rooted in the family's rules, beliefs, values, and culture.

Central to the Circumplex Model are three key dimensions: **cohesion, flexibility, and communication**. A family can be described as functioning on a continuum across two of these dimensions, cohesion and flexibility. **Cohesion** is defined as the “emotional bonding that family members have towards one another (Olson, 2000, p. 145). A family's cohesion can range from disengaged to enmeshed, with separated and connected cohesion falling within the middle range. Family **flexibility** refers to “the amount of change in its leadership, role relationships and relationship rules” (p. 147). Olson's definition of flexibility is built on the notion that a system creates a balance between stability and change. A family's interaction patterns, often predictable and repetitive, help the system to maintain its equilibrium and functioning. However, there are times when a family experiences a disruption to the system (e.g., the birth of a child) and it works to incorporate the change (the child) into the family unit and restore the balance. A family's negotiation style, relationship rules, and relationship roles are underlying aspects of the concept of flexibility. According to the Circumplex Model, a family's flexibility patterns can either be rigid, structured, flexible or chaotic with structured and flexible patterns perceived as ideal for healthy family functioning.

The third dimension, **communication**, is considered to be critical to the other two. According to Olson, communication is a “facilitating dimension” (p.149). Components of communication include listening skills, speaking skills, self-disclosure, clarity, continuity tracking, respect and regard. Within this “facilitating dimension,” the family determines its adaptability the family is to the stressor (such as a disability) and how it will cope to the change in the system. Communication is the dimension that enables all members of the family system to interact and transact with one another. Without good communication between family members the opportunities for strong cohesion and flexibility are challenged.

Communication as the Link

Olson’s (2000) dimension of communication is a complementary concept to both the Circumplex Model and Transactional Model. Communication is key for flexibility and cohesion within a family. Applied to the Transactional Model, communication informs how the family responds to stressors (e.g., ASD) through the bi-directional and mutually influential interactions between family members. Communication as a connecting dimension, assists the family in adjusting to changes in their stability (via flexibility and cohesion) in order to move towards equilibrium (Lavee & Olson, 1991).

Family dynamics and functioning center around the environment/enviromtype which includes the attitudes, beliefs, and norms about any given stressor, and the transactions that occur which relate to coping and adaptation. In particular, Olson (2000) notes that a family’s ability to cope varies according to the *source* of the stress, the *outcome* of the stress, the *appraisal* of the stress, and *resources* available to the family (both internally and externally).

With respect to families of children with ASD, multiple or cumulative stressors can have a profound impact on their functioning. Most families are not prepared for the disability, and likely

do not initially have or know how to locate the supports and resources (emotional and concrete) needed to offset the unexpected disruption to the family's equilibrium. The outcome for the family in relation to the stressor (i.e., ASD) is, in large part, dependent on how the family perceives and responds to the stressor and on the resources available to the family. The accommodations and adjustments the family makes as they adapt may be isolated to one family subsystem or throughout (Minuchin, 1974).

ASD and Sibling Relationships

The sibling bond and relationship is pivotal within the family. Much of the research has been conducted on a normative population, with some studies focused on families of children with disabilities. Researchers looking at siblings of children with disabilities (SIBS-DD) have primarily examined adjustment (mental health and behavioral outcomes) to a sibling with a developmental disability (Giallo & Gavidia-Payne, 2006; Meadan, et al, 2010; Orsmond & Seltzer, 2007; Van Piper, 2000). In the last 10 years there has been an increased interest in sibling relationships in F-ASD (Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006).

Siblings serve multiple roles in the family, including support, peer companion, playmate, confidant, social model and teacher (Herrera & Dunn, 1997; Kitzman, et al., 2002). These relationships are considered to be highly significant, second only to the relationship with parents (Furman & Buhrmester, 1985). Siblings provide a unique level of social and emotional support to one another. Among other benefits, sibling relationships have been found to provide a protective factor in family dynamics (Kramer & Kowal, 2005). For example, positive sibling relationships have been found to have a buffering effect on the impact of high conflict homes. In a cross-sectional study, Jenkins and Smith (1990) found that the quality of sibling relationships had a

moderating effect on the impact of high conflict marital relationships on child outcomes. In particular, when positive sibling relationships were present, there were no statistically significant associations between marital conflict and negative child outcomes. The sibling relationship has also been linked to the adjustment of family members to stressful life events (acute, short-lived stressors such as death, home moves, and school challenges). In a longitudinal study, Gass, Jenkins, and Dunn (2007) found that siblings with more positive relationships had less of a change in internalizing behaviors when faced with a stressful life event in comparison to siblings with less warm relationships with one another.

Given that having a child with a disability may increase family stress and influence the dynamics of the other family relationships, it is important to understand sibling relationships in these families. In this next section, I present research on facets of the sibling relationship that shape the dynamics within the subsystem, with a particular eye to siblings in F-ASD.

Child Characteristics and Links to Quality of Interactions

Sibling dynamics are shaped by a number of factors including individual child characteristics, such as gender, age, birth order, and temperament (Ainsworth, 1978; McHale et al., 2001; Yu & Gamble, 2008). The impact of sibling temperament styles has been examined in the literature; defined in terms of self-regulation/effortful control/ behavioral inhibition and negative affectivity (Rothbart, Ahadi, & Evans, 2000). Sibling conflict is often utilized as one measure of relationship quality. Researchers have found that when siblings have more similar temperament styles (in particular, low activity temperaments), they tend to have less conflict in their interactions with each other (Munn & Dunn, 1989; Stoneman & Brody, 1993). On the other hand, preschool and school-age children who exhibit high activity and emotional intensity have been associated with more negative sibling relationships (Lemery & Goldsmith, 2001; Stoneman & Brody, 1993). The

influence of similar versus different temperament is a particularly interesting dynamic when considering its contribution to sibling relationship quality in families of children with disabilities.

Siblings of children with disabilities. Researchers have found that children with ASD tend to have more difficult temperaments (Kasari & Sigman, 1997), to be less persistent (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000; Hepburn & Stone, 2006), and to have lower effortful control (Konstantareas & Stewart, 2006) than typically developing children or children with other disabilities. To date, there have been only a few studies on the influence of temperament in children with ASD (i.e., Kasari & Sigman, 1997; Rivers & Stoneman, 2008) in relation to their sibling interactions.

Rivers and Stoneman (2008) explored aspects of child temperament (such as negative emotionality, activity level, persistence, and behavior inhibition) and sibling relationships in fifty F-ASD. They found that persistence (sustained attention to tasks even when they are challenging) was a predictor to sibling relationship quality, such that, when the typical siblings demonstrated higher persistence, the sibling relationship was less negative. Per parent report, these siblings demonstrated less unkind behaviors, less avoidance/embarrassment, and higher empathy. Relationship quality and satisfaction were lowest when both children were low in persistence. It may be that the low persistence in each child aggravated this quality in the other. Rivers and Stoneman also suggest that temperament may be a buffer to sibling relationship quality. When the other sibling had a more positive temperament, it minimized the negative impact of the more “difficult” child on the sibling system.

For all families, individual characteristics inform interaction styles and communication patterns that are developed between family members. Communication patterns are established through the mutual influence of each person including his communication abilities. This is

particularly relevant for sibling pairs of children with ASD and other developmental disabilities in which social-communication deficits are at the core of the disorder.

There is research to suggest associations between the social-communication abilities of children with ASD and their siblings. For example, Yirmiya et al. (2006) examined the cognitive, social engagement, and communication patterns of infant siblings of children with (SIBS-ASD) and without autism (SIBS-TD). Measures included 1) developmental and communication scales (e.g., Bayley Scales of Infant Development, Early Social Communication Scales, Checklist for Autism in Toddlers), 2) infant affect and attention tasks (i.e., still face procedures, infant gaze, name recognition/response) at 4 and 14 months, and 3) observation of mother-infant synchronous play. At 4 months, the researchers determined significant differences between the two groups. SIBS-ASD had fewer infant led synchronous mother-child free play interactions (a consistent finding at 4 and 14 months) and they tended to show less reactivity to the still-face procedure compared to SIBS-TD. One significant difference between SIBS-ASD and SIBS-TD was with infant affect. During the still-face procedure, SIBS-ASD demonstrated a more neutral affect. Associations between 4-month affect and 14-month joint attention revealed a significant association for SIBS-ASD, indicating those who demonstrated more neutral affect at 4 months also exhibited less initiated joint attention at 14 months. In sum, SIBS-ASD were found to have communication and social engagement patterns consistent with children with autism. Similar results have been found in the social-communication patterns of younger siblings of children with autism (Cassel et al., 2007; Landa & Garrett-Mayer, 2006; Zwaigenbaum et al, 2005).

Genetic factors and ASD. There is growing evidence for a genetic basis to ASD (Rutter, 2000; Wassink et al, 2004). This is especially pertinent in discussing the influence of child characteristics on sibling relationships. Sibling and twin studies have surged as researchers

investigate possible genetic links to ASD. The influence of multiple births and ASD gains further importance when looking at the trend in multiple births in the general population. Statistics indicate that multiple births have increased over the years with 1 in 30 twin births in 2009 compared to 1 in 53 in 1980 (CDC, 2012). According to the U.S. Census data of 2009, the twin birth rate in the United States was 33.2 per 1,000 (Martin, Hamilton & Osterman, 2012). Moreover, the rate of triplet and higher order multiple births (quadruplets, quintuplets, sextuplets and septuplets) was 153.5 per 100,000.

As researchers explore the links to ASD via twin studies, they are finding multiple possible risk factors for the disorder, including maternal and paternal age, low birth weight, and being a twin (Kates et al., 2004; Gardener, Spiegelman & Buka, 2009, 2011; LeCouteur et al, 1996; Rutter et al, 1997). Research has found that the risk for siblings of individuals with ASD is 45 times greater than the general population (Lord, Leventhal & Cook, 2001). Multiple studies suggest identical twins have a 36-91% chance of both twins having autism, while fraternal twins have a 0-24% chance of both twins developing autism (Bailey et al., 1995; Folstein & Rutter, 1977; Steffenburg et al., 1989). Gardener and colleagues (2011) conducted a meta-analysis on 40 studies looking at perinatal and neonatal factors in the risk for autism. Although the authors found inconsistent results between studies, they were able to find a few factors with the strongest evidence for a relation to the risk for autism including multiple births (twins, triplets, etc.), maternal bleeding, and low birth weight or small for gestational age. It is important to note that research has not indicated any one birth complication that has been found to increase the risk of autism.

In connection to research on early diagnosis of ASD, more studies are being conducted on infants and toddlers of siblings already diagnosed with the disorder. Some of the findings (e.g., Landa & Garret-Mayer, 2006) reveal that younger siblings are more likely to be diagnosed with

autism at a future point in time than other children. Goldberg et al. (2005) compared undiagnosed younger siblings (average age of 17.1 months) of children with ASD to two groups of children: 1) children diagnosed with ASD (average age 29.9 months), and 2) typically developing children with no familial ASD (average age 15.3 months). Structured interactions were used to measure siblings' nonverbal communication in three domains: social interaction, joint attention, and behavioral regulation. Measures of response to social interaction, initiating joint attention, and requesting behaviors for undiagnosed siblings of children with ASD were more similar to the children with ASD than they were to typically developing children.

Toth, Dawson, Meltzoff, Greenson and Fein (2007) explored the social, imitation, and language skills of infant siblings of children with autism compared to siblings of children with no history of autism. Observations, developmental measures, and other direct tests of child skills yielded group differences in the communication areas of language, social communication, and social-emotional functioning. In particular, siblings of ASD children had a slower rate of communication, scored lower in receptive language skills, and used fewer social gestures and social smiles. The findings from these studies are useful to the understanding of how individual characteristics (e.g., competence and skill level) intersect to shape interaction patterns between siblings, which in turn, influence other aspects of the sibling relationship such as bonding, conflict, and adjustment.

Sibling Conflict

Some level of conflict generally occurs in most sibling relationships (Ostrov, Crick, & Stauffacher, 2006) and may be related to the roles of each member in the system as well as perceptions of inequity in the system. Sibling rivalry and conflict have been used as indicators of the quality of bonding between siblings and their attitudes about the relationship. Conflict,

however, does not necessarily produce negative outcomes. It often provides siblings opportunities to develop prosocial skills (i.e., conflict resolution and emotional understanding) and stronger ties to one another as they work through challenges (Brody, 2004). The roles that are assumed or assigned can shape the quality of the relationships especially as it relates to the reciprocal (the mutual exchanges that occur between siblings) and complementary (the hierarchical nature of sibling relationships—such as birth order or other form of authority in the relationship) nature of the dyad (Dunn, 1983), as siblings manage and resolve conflict in their relationships (Rinaldi & Howe, 1998).

Related to the complementary aspect of birth order (hierarchical nature of the relationship), power has shown to be a factor in conflict resolution between siblings. For example, Tesla and Dunn (1992) found that the older siblings of preschoolers tended to use less compromise and bargaining with their siblings. Similarly, through observations, Martin and Ross (1995) found that preschool aged older siblings tended to be more aggressive with their younger siblings. School-age and adolescent sibling dyads have been described as utilizing other-oriented conflict resolution strategies, where they considered the perspective of their sibling (Ram & Ross, 2001). Regardless of the strategies utilized, it has been found that older siblings have more control over the positive or negative outcomes of the exchange (Buhrmester & Furman, 1990; Ram & Ross, 2001).

Sibling relationships are also influenced by dynamics within the context of the larger family. For instance, child perspectives on parents' differential treatment of siblings are shown to influence the sibling relationship (Brody, 2004). Many of the findings suggest that differential parenting (actual or perceived) can contribute to negative outcomes for the sibling relationship such as increased competition and conflict (McHale, Crouter, McGuire, & Updegraff, 1995; Stocker, Dunn, & Plomin, 1989; Volling & Belsky, 1992). Conflict between siblings has been associated with

negative mental health outcomes (Stocker, Burwell, & Briggs, 2002). Conversely, warm relationships are positively correlated with positive outcomes (Kim, McHale, Crouter, & Osgood, 2007). Conflict management and related attitudes about the sibling relationship are important to all sibling systems, but become even more salient when one child has a disability. Not only is the strength of mutuality between siblings relevant, but so is the congruency of abilities to resolve conflict.

Siblings of children with ASD and other disabilities. Similar to the general population, differential parenting (actual or perceived) has also been identified as a common occurrence in families of children with disabilities, many times with parents showing favor to the child with the disability (Lobato, Miller, Barbour, Hall, & Pezullo, 1991; McHale & Pawletko, 1992; Quitter & Oipari, 1994). There have been very few studies on conflict resolution strategies between siblings in families of children with disabilities. Nonetheless, studies of typically developing siblings (Martin & Ross, 1995; Ram & Ross, 2001; Tesla & Dunn, 1992) may provide insight into the possible conflict resolution patterns of siblings in families of children with disabilities. Although power and influence in typically developing siblings (SIBS-TD) may be strongly influenced by birth order and chronological age, this may not be the case for siblings of children with disabilities (SIBS-DD). Instead, functional age and ability may be the more salient factor (especially for children with cognitive disabilities). In other words, birth order/age (SIBS-TD) and functional age/ability (SIBS-DD) may represent the same overall construct-- the standard for sibling hierarchy (power and influence). It is possible that the actual conflict resolution patterns for both groups could be very similar within their respective sibling hierarchies. Age, birth order, and gender have been found to be significant contributors to sibling relationships in families of children without disabilities. These characteristics combined with disability status, adds to the complexity of sibling

dynamics. For instance, researchers have found that when one sibling has a disability, and if the dyad is close in age or opposite gender, they are at greater risk for conflicted sibling relationships (Begun, 1989; Orsmond & Seltzer, 2000). It is important to note that for ASD sibling pairs, the social-communication-behavioral impairments for the child with ASD (reciprocity, emotion regulation, and behavioral flexibility), compromises the dyad's ability to utilize communication as a tool to resolve conflict (Guralnick, Connor, Hammond, Gottman, & Kinnish, 1996; Lieber, 1993).

Siblings of children with ASD have been found to experience unique challenges to their sibling relationship, especially related to conflict. Ross and Cuskelly (2006) found aggression from the ASD sibling to be a reported stressor (by the typical sibling-84%) on the sibling relationship. The typical siblings reported anger to be the most common response to the aggression, leading to some coping strategies that reduced the level of interaction with their ASD siblings (such as withdrawal or resignation). The adjustment of typical siblings to having a brother or sister with a disability, and the connection to sibling interactions (such as conflict or aggression) is further noted in a quantitative study conducted by Cuskelly and Gunn (2006). The authors compared interactions between 53 siblings of children with Down Syndrome (DS) and those without disabilities. The authors found connections between the typical sibling's internalizing and externalizing behaviors and his interactions with his brother/sister. Based on the results from self-report and parent-report measures, no significant differences were found in the adjustment of siblings of children with DS and those of typically developing children. A noteworthy discovery was uncovered with siblings of children with DS. The authors found a moderate correlation between parent reports of the child's "unkindness" toward their sibling and externalizing behaviors. These findings suggest the siblings who demonstrated less compassionate behaviors (in general) also tended to have less positive interactions with their siblings with DS.

Sibling Adjustment, Bonding, and other Connections to Quality of Interactions

Adjustment. A sibling's adjustment to a disability (influenced by his understanding of the disability) and his perspective about his brother or sister, affects the nature of the interactions between the dyad. Researchers have found that SIBS-DD may experience a myriad of feelings, including depression, loneliness, anger, guilt, sadness, disappointment, resentment, and behavioral adjustment problems (Giallo & Gavidia-Payne, 2006; Kaminsky & Dewey, 2002; Nixon & Cummings, 1999; Rossiter & Sharpe, 2001). Conversely, some studies (e.g., Dew, Balandin, & Llewellyn, 2008) have found little difference in the outcomes and adjustment of SIBS-DD compared to SIBS-TD. Moreover, researchers have found that typical siblings may develop increased tolerance and understanding as a result of having a sibling with a disability (Stainton & Besser, 1998). Mascha & Boucher (2006) conducted a qualitative study with eleven families and found that many siblings experience mixed feelings and their outlook is tied to the quality of the sibling relationship. The authors found that SIBS-ASD reported both positive interactions with their siblings (had fun with the brother or sister) as well as negative feelings about the sibling with ASD (e.g., embarrassment). These and other studies (Macks & Reeve, 2007; Roeyers & Mycke, 1995; Verte, Roeyers, & Buysse, 2003) demonstrate the complexity of experience SIBS-DD may face. Some of the contradictory findings may be explained by differences in disabilities. In a recent review of the literature on the adjustment of siblings of individuals with ASD, Meadan, Stoner, and Angell (2010) suggest that the mixed findings related to these siblings' adjustment may similarly be related to the varying control-contrast groups represented in the studies (see study for a detailed review of the literature).

Sibling relationships in F-ASD have been compared to those in families of children with intellectual disability, such as Down syndrome (DS) (e.g., Fisman, Wolf, Ellison, & Freeman, 2000; Kaminsky & Dewey, 2001; Knott, Lewis, & Williams, 1995). Kaminsky and Dewey (2001) found that the siblings of children with ASD and DS (90 siblings total) had more admiration and less competitiveness and strife compared to typically developing sibling pairs. In comparisons of thirty ASD and DS sibling dyads, Knott et al. (1995) found that ASD sibling pairs had fewer prosocial initiated interactions (fewer verbal exchanges or behaviors related to sharing, cooperation, affection, etc.) than DS sibling dyads. Similarly, the ASD siblings responded less to their siblings' prosocial initiations compared to DS siblings.

A longitudinal study (Fisman, et al., 2000) provides insight into the stability of sibling relationships over time. The authors studied siblings of children with ASD (pervasive developmental disorder), DS, and no disability, over a three year period. Through comparisons of the three groups, siblings of ASD children were found to have more adjustment problems compared to the other two groups, consistently through all time points. An explanation offered for these results was that ASD families may have a "characteristic profile of stress" (Fisman et al., 2000, p.373), with different sources of stress and a greater intensity of stress. While explanations were discussed more in terms of parental adjustment, it would also be worthwhile to examine this explanation in terms of siblings. Another possible explanation for these findings is that the less physically visible characteristics of a disability (e.g., the "invisible" nature of ASD) present unique challenges to siblings' understanding, coping, and response to their brother or sister (Glasberg, 2000). A few recent qualitative studies on sibling adjustment in F-ASD have described sibling accounts marked by a wide range of experiences, both positive and negative, such as stressful life situations, negative impacts on daily life, community prejudice and rejection, feelings of anxiety

and embarrassment, acceptance of sibling's disability, and pride/positive feelings towards sibling with ASD (Benderix & Sivberg, 2007, Moyson & Roeyers, 2011; Petalas et al, 2009).

Bonding. The functioning and adjustment of the larger family system to a child with a disability, including level of burden felt, acceptance of the disability, and care-taking responsibility, have been found to contribute to sibling relationship quality. For example, Weigner (1999) found that for both siblings and mothers of children with intellectual disability (ID), there was a positive correlation between their view of the child with ID and their perspectives about family functioning. Perceived family burden related to caring for the disabled sibling was associated with lower ratings of family functioning. Sibling perceptions (i.e. perceived burden or acceptance) are largely tied to the level of satisfaction and bonding that occurs between the pair.

The sibling bonding and socialization that typically occurs may be disrupted and/or altered due to a sibling's disability. Role responsibilities, role reversal or cross-over, incongruent ability/functioning levels, and feelings of resentment (all noted as a common occurrence in families of children with disabilities) can affect bonding. The typical roles of confidant and peer playmate may not be so typical for SIBS-DD. Roles may expand to include childcare (Cuskelly & Gunn, 2003). When this occurs, power shifts, creating a less symmetrical relationship that may extend into and throughout adulthood (see Orsmond & Seltzer, 2007 and Stoneman, 2005). Role cross-over/role reversal may occur for SIBS-DD at a young age. Typically developing, younger siblings often eventually cognitively and socially surpass their older sibling with a disability. When this occurs, the older-younger sibling dynamics and socialization patterns (including role dominance) shift (Brody, Stoneman, Davis, & Crapps, 1991).

The complex nature of ASD is such that the core traits may work against the bonding between siblings. A disability, and the associated impairments, is likely to influence the mutuality

within the sibling relationship. Satisfaction with the sibling dynamic (general population or disability) is largely dependent on the children's ability to engage in mutually gratifying activities. The impairments found in ASD (poor social reciprocity and limited repertoire of play skills) and other disabilities can present a challenge to this goal (Knott et al, 1995; Strain & Danko, 1995). Whereas some researchers have found negative outcomes for siblings (Ross & Cuskelly, 2006), others have found that ASD sibling relationships can be relatively close and positive, especially when the typical siblings have social support (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003).

Siblings' feelings of resentment have also been found to be a factor important in bonding. For typical sibling dyads, resentment often occurs due to perceptions of differential parenting or other forms of inequity. In families of children with disabilities, the issue of resentment has additional layers including role strain and responsibilities. Siblings that experience role strain (stress of fulfilling multiple roles) and/or social isolation/limitations have been found to have less positive interactions with their brother or sister with disabilities (see Stoneman, 2005).

Family Influences on Sibling Relationships

Central to ecological system theory as well as general family system theory (Bronfenbrenner, 1986; Minuchin, 1974; Minuchin, 1985; Olson, 2000; Sameroff, 2009) is the bi-directional or transactional influence within the family unit, and the interconnectedness between family subsystems. The identified "spill over" associations (Erel & Burman, 1995) suggest that the functioning of one combination of family relationship (e.g., parent-child) "spills over" into the others. There is a dearth of research on the bi-directionality of influence between parent-child, marital, and the sibling relationships in families in the general population (Brody, Stoneman, & McCoy, 1994; Pike, Coldwell, Dunn, 2005).

There is an abundance of empirical research which suggests that aspects of the family emotional environment (such as marital conflict, parent and household stress, and family chaos) have been associated with conflict or lower relationship quality in sibling relationships (Brody, Stoneman, McCoy, & Forehand, 1992; Cui, Gonger, Bryant, & Elder, 2000; Kretschmer & Pike, 2009; Yu & Gamble, 2008). For example, marital satisfaction and low marital discord have been associated with less sibling conflict and more positive interactions (Brody, et al. 1992; Brody et al., 1994; Yu & Gamble, 2008). Family subsystems, marital quality and sibling relationships have been found to be mediated by parent-child interactions (Stocker & Youngblade, 1999). Sibling adjustment in relation to parental stress has also been explored in the larger discussion of family functioning. In studies of families in the general population (Boer & Dunn, 1992; Brody & Stoneman, 1987; Brody et al., 1994; Stoneman & Brody, 1993) as well as of families of children with disabilities (Rivers & Stoneman, 2003), the quality of sibling relationships has been closely linked to the quality of other relationships in the family (i.e., marital and parent-child).

Rivers and Stoneman (2003) examined the effects of problems in the couple subsystem (marital stress) on the sibling subsystem, in F-ASD. Via self-report measures and questionnaires, the authors found that high marital stress was associated with decreased positive sibling relations. However, another interesting finding was that families' use of both formal and informal social supports served as a buffer to the negative impact of higher marital stress on sibling relationships. Moreover, even with the challenges to the sibling system, the typically developing siblings rated their overall sibling relationships as positive. This is similar to other studies with findings to suggest that disabilities can also foster positive family relations (e.g., Kaminsky & Dewey, 2001).

Sibling ties are complex and interwoven with several factors related to the family constellation. One of the most common factors that have been studied in sibling relationships is parent-child interactions. Some of these issues will be highlighted in the next section.

ASD and the Family: Other Interactions with Family Members

Parent-child Relationship

A diagnosis of ASD presents challenges to a child's ability to communicate. These impediments to interactional quality can disrupt the connectedness between the child and his parents (as well as other combinations of child(ren)-adult interactions). One aspect of parent-child cohesion can be seen through the emotional regard (attitudes, thoughts, or feelings about the nature of a person) of caregivers toward their children (Greedharry, 1987; Hastings & Lloyd, 2007), known as expressed emotion (EE). EE is evaluated on a continuum of low to high based on the quality and content of parents' comments about their child (hostile, critical, emotional over-involvement, warmth, and positive remarks). Higher levels of EE would indicate more hostile or critical comments made related to the child. This attitudinal construct was first developed examining families of individuals with schizophrenia (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) but has expanded to other populations with chronic mental illness, depression, and certain medical conditions. A small number of EE studies have been conducted on families of individuals with developmental disabilities or ASD. A gap in the existing literature on EE and disabilities is its historical focus on children over the age of 14 (Dossetor, Nicol, Stretch, & Rajkhowa, 1994; Greedharry, 1987; Hastings & Lloyd, 2007). To date, only four EE studies of individuals with disabilities have included children under the age of 10. Of these, only one was specific to autism (see Hastings & Lloyd, 2007 for a full review).

Beck, Daley, Hasting and Stevenson (2004) investigated a sample of parents of young children with either autism or Down Syndrome (both classified as “Intellectual Disability [ID]”). The authors looked at a number of factors associated with EE, including parenting beliefs, parenting satisfaction, and child behavior. They found that 60% of the mothers reported higher levels of EE toward the child with ID compared to their 2nd, typically developing child. Interestingly, parents rated as high EE had children with more reported behavioral problems. These problematic behaviors were also perceived as having a more negative impact on the family as a whole. Two limitations of Beck et al. (2004) and other EE studies are the lack of direct observations of the parent-child interactions, and the classification of autism and Down syndrome under the same category of ID. The findings were not specific to the two distinct disabilities; therefore, it is difficult to determine if there are differences in the EE of mothers based on the particular disability and/or level of severity of behaviors in the child. However, even with these constraints, this study provides a window into the quality of interactions and connectedness that may occur between parents and their children with disabilities.

Parent-child communication patterns. Parent communication and interaction patterns with their children may differ from child to child for many reasons, including gender and birth order (Baskett, 1984; Beck et al., 2004; Keller & Zach, 2002). For example, in the general population, parents have been found to favor first-born children, as well as exhibit a same sex preference [mothers to daughters; fathers to sons] (Keller & Zach, 2002). Findings from other studies indicate a relationship between birth order and level of interaction between siblings and parents: younger siblings engage equally with their older siblings and parents; older siblings engage more with their parents (Baskett, 1984).

A child's social-communication abilities (such as reciprocity) have been shown to contribute to the quality of parent-child interactions. In families where children have diverse communication abilities (whether due to chronological age or disability) unique parent-child communication patterns may develop. These patterns of engagement may adapt depending upon the composition of the communication circle (e.g., parent-child vs. parent-child-sibling).

Woollett (1986), for example, examined the verbal exchanges between parents and their children (younger child and an older sibling). Woollett found that when a triad was present, consisting of the mother, the younger child, and the older sibling, there was a 70% decrease in maternal language to the infant child and also a decrease in the infants' utterances by 50 %. It is important to note that there are several possible explanations for this result. For example, the more verbally adept sibling could have more verbal/social exchanges with the parent, due to the greater ease of communication. Subsequently, the parent may 1) direct more of her attention towards the sibling, or 2) defer to the sibling as the "translator" for the child with communication challenges.

Barton and Tomasello (1991) contribute to the evidence that parent-child interactions may be impaired when a child has less developed language skills. Unlike Woollett (1986), in this observational study the authors found that the three-way interactions (parent-infant-sibling triad) yielded longer conversations between the mothers and infants. However, this finding does not discount the possibility that the mother-infant interactions could have been of lesser quality and shorter length if the preschool-aged sibling had not been present. In fact, the authors partly attribute the increased length of conversations to the addition of the sibling and the increased opportunities for turn-taking he/she presented.

These studies are useful for understanding the challenges with parent-child interactions with less verbally skilled children, and the advantages a second, more verbally adept child, brings to the

system. The examination of the communication exchanges between mothers and their children at different stages of language development can provide increased understanding and application to children with disabilities. There may, however, be other dynamics at work when the deficit in communication skills of a child older than an infant/toddler is due to a disability versus the emerging communication skills of an infant. Parents may be more understanding and supportive of a baby learning to talk, compared to an older child (where this is a constant reminder of the disability). Notwithstanding, these studies help to explicate how higher functioning siblings may serve as social models and helpers to both their sibling and parent--serving as “translators.”

Mother versus father interactions. The examination of the unique interaction styles of mothers and fathers with their children (with and without disabilities) has been a neglected area of research. Historically, fathers have been minimized in the child development literature. Although advances have been made in incorporating fathers more in research (Cabrera, Tamis-LeMonda, Bradley, Hofferth & Lamb, 2000; Fagan, Palkovitz, & Roy, 2009; Tamis-LeMonda & Cabrera, 1999), there is still much to be learned about father involvement, especially in families of children with disabilities. However, we can draw on research from the normative population of children to learn more about potential interaction effects of mother and father relations with children with disabilities.

Associations between child gender and level of parental involvement have been noted in the literature. Researchers have found a tendency for mothers to interact more with daughters, whereas fathers’ interactions are more likely to be with sons (Crouter & McHale, 1995; Lamb, 1997). Lamb et al.’s (1985, 2000) models of paternal involvement identifies several dimensions for understanding the father-child experience. Personal *interaction* (direct contact with the child), *accessibility* (physical and emotional), and *responsibility* (care-giving) are components of

involvement. These interactions are influenced by a number of factors, including the traits and behavior of the child (McBride & Rane, 1998; McBride, Schoppe & Rane, 2002). Thus, the roles parents take in the household as well as child characteristics may inform the nature of the parent-child interactions.

McBride, Schoppe, and Rane (2002) examined associations between parents' perceptions of their child's temperament and behavior, the stress of parental roles, and the amount of involvement in care-giving. Key findings from the self-report and interview data of 100 parents give evidence that there are differences in mother's and father's involvement with children, depending on child characteristics (as perceived by the parents). For fathers, the gender of the child had strong associations with level of involvement. For instance, less social girls elicited less involvement from fathers, but not so with male children. Yet, mothers' level of involvement was relatively stable across gender. Various associations were found between parent stress and child behavior and temperament. Both mothers and fathers reported less stress for children exhibiting low emotional intensity. However, in comparing parental stress for high versus low emotional intensity, the gender of the child was a central factor. Fathers were more affected by the emotionality of female children, and the reverse was true for mothers. The social ability of children was an influential aspect in father stress. More sociable children were perceived as less stressful for fathers, however, there were no associations for mothers. Conversely, mothers found less active children to be less stressful, whereas fathers were not affected by activity level. These overall findings help to show how the intersection of parent gender, child gender, child behavior, and parent stress impacts the level of involvement of parents with their children (and indirectly, the quality of the parent-child relationship).

The findings from this research offer insight into families of children with disabilities. The dimensions of child behaviors (child activity, adaptability, approach/withdrawal, emotional intensity, distractibility, and persistence) measured by McBride et al. (2002) capture some of the behavioral characteristics of certain disabilities including ASD.

Reciprocity and synchrony. A child's ability to engage in reciprocal interactions is essential to his receiving the necessary social-emotional feedback from his caregiver. For the typically developing child, early attachments between the child and mother are dependent on the reciprocity and responsiveness between the dyad (Ainsworth, 1978; DeWolff & van Ijzendoorn, 1997; Maccoby & Martin, 1983; Ranson & Urichuk, 2008). This shared interaction, discussed in terms of shared positive affect (SPA), synchrony, and reciprocity has been linked with various positive child outcomes including increased social skills, emotion regulation, and communication skills (Kochanska & Aksan 1995; Kochanska & Murray 2000; Laible & Thompson 2000; Lindsey, Creemens, Colwell, & Caldera, 2009). When children do not offer positive social feedback to parents, parents are less likely to interact with the child and provide social modeling (Campbell, 1995).

Children with disabilities often have compromised social interaction skills (Kutnick & Kington, 2005) which can have an effect on their bonds with parents. A combination of factors impact the quality of the parent-child relationship including: 1) the child's social-communication abilities, 2) the parent's own level of responsivity, and 3) the parent's ability to adapt and accommodate to their child's level of responsiveness. For example, Baker, Blacher, and Olsson (2005) found that more optimistic mothers were better able to cope with the challenging behaviors of their children with intellectual disabilities. These factors have significant implications for the parent-child outcomes.

Several studies have linked parent-child interaction quality to child behaviors. For example, Keown and Woodward (2002) found direct associations between parent-child communication and pervasive hyperactivity in preschoolers. Comparing the parent-child relationships (via interview, questionnaire, and observation) of families of preschoolers with (33 boys) and without (34 boys) diagnosed hyperactivity, the researchers assessed the interactional synchrony of the dyads (defined as responsive, connected, reciprocal, mutually focused and harmonious). The parent-child dyads of the pervasively hyperactive children had statistically significant lower communication and interactional synchrony compared to the matched sample.

Reciprocity and synchrony are also central to understanding relationships between parents and children with ASD. A large portion of the empirical research on these interaction dimensions have been performed within the context of developing social-language interaction skills in children (Bauminger, 2002; Greenspan & Wieder, 2007; Horner, Carr, Strain, Todd, & Reed, 2002; Soloman et al, 2008). Yet the field has in general neglected to expand the examination of how these skills guide parent-child social dynamics. A few researchers have begun to explore some of these dynamics. For example, in their empirical study, Siller and Sigman (2002) found that parents of children with autism were similar in their level of synchrony with their children compared to parents of typically developing children or children with developmental delay-- matched on the child's language abilities. This longitudinal study also revealed that children with autism, who had mothers with higher levels of synchrony had better joint attention and language development over time. Siller and Sigman (2008) similarly found that children's language growth over time was related to the child's responsiveness to bids for attention (from others), in addition to their parents' level of responsiveness and synchrony to the child's interests and activity during play. While

children's language development and skills are noteworthy to the discussion of parent-child dynamics, they will not be addressed in this review.

Parental, Marital, and Overall Family Dynamics

A better understanding of how ASD affects the daily lives of families has been explored in several qualitative studies. Hutton and Caron (2005) found that more than half of the parents interviewed in their study reported the stress of parenting a child with ASD compromised even the most basic aspects of family life. For example, parents reported having less time for family activities and needing to plan ahead for even simple activities, thus affecting flexibility in many aspects of family life. Other researchers have noted similar family experiences, citing fewer family vacations and outings (Montes & Halterman, 2007). In a longitudinal study, (e.g., Gray, 2002) found that behavioral issues associated with ASD were identified as an ongoing issue in family life, functioning and dynamics.

There is a paucity of research on ASD and the couple/marital relationship. The available literature has been mixed in terms of the outcomes found for these couples. For some couples, the issues surrounding the disability may negatively test or strain the marital relationship (Risdal & Singer, 2004; Withers & Bennett, 2003). However, in other studies, it has been found that the shared burden may serve to bring couples (and the larger family unit) closer together as they work to meet the needs of all members and maintain family connectedness (Heiman, 2002; Stoneman & Gavidia-Payne, 2006). Some studies show that parents of children with ASD have lower marital satisfaction, less flexibility and adaptability, and diminished warmth/connectedness (Higgins, Bailey, & Pearce, 2005). Conversely, other meta-analytic studies have found a comparatively small difference in marital adjustment between couples of children with and without disabilities (Risdal & Singer, 2004).

Caregiving burden, parental mental health, employment, and financial stress are frequently discussed stressors faced by parents of children with ASD and other disabilities (Esbensen, Seltzer & Greenberg, 2006; Kersh, et al., 2006; Lewis, Kagan, & Heaton, 2000; Montes & Halterman, 2008; Porterfield, 2002; Rosenzweig, Brennan, & Ogilvie, 2002; Rosenzweig & Huffstutter, 2004; Turnbull, Summers, Lee & Kyzar, 2007). Studies on F-ASD have found that the emotional stress placed on parents (due to caregiver burden and the challenging needs of the child), can significantly impact parental functioning, with these parents reporting higher levels of stress, anxiety, and depression (Gray 2002; Montes & Halterman, 2008; Schieve et al, 2007). Findings have been mixed related to the functioning of parents of children with ASD in comparison to other disabilities. Some researchers have found that the stress experienced by parents of children with ASD is higher than parents of children with other disabilities or no disabilities (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Dunn, Burbine, & Tantleff-Dunn, 2001; Montes & Halterman, 2007; Olsson & Hwang, 2001; Weiss, 2002; Sivberg, 2002), while others have reported comparable levels of stress in F-ASD and other intellectual disabilities (Baxter, Cummins, & Yiolitis, 2000). One reason for these discrepancies may be due to the range of functioning within ASD (severe autism to Asperger's Syndrome). The level of stress experienced by families may be influenced by the severity of the disorder.

Differences in stress between mothers and fathers of children with ASD have just started to be explored. Consistent with parenting research in general, much of the ASD research has focused primarily on mothers. When fathers are included, researchers have found mixed significant difference in the stress levels of mothers and fathers of children with ASD (Benson, 2006; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008), while others have found mothers experience higher levels of stress than fathers (Hastings, 2003b; Herring et al, 2006; Little, 2002).

Conclusion

This review of the literature demonstrates the significant impact ASD can have on the family system. Much of the available literature on ASD has been focused on child outcomes with a narrow focus on family functioning. This is a fundamental gap in the literature. Although the topic of disabilities has historically been approached highlighting the challenges and disruption a disability brings to the family, researchers have increasingly recognized the successful and resourceful ways in which families adapt to adversity (Stainton & Besser, 1998).

While the field is learning more about ASD, child outcomes, and some aspects of family outcomes (i.e., parental stress, the coping and adjustment issues for the typical sibling, etc.), there is still limited literature on the nature of sibling interactions and bonds in F-ASD. Moreover, the perspectives of children with ASD on their sibling relationships are virtually uncharted.

Chapter 3: Method

In this chapter I discuss the methods of data collection and analysis. I will describe the participant selection and recruitment, data collection, and data analysis.. A discussion of the potential ethical issues and personal considerations are also presented.

Overview

The purpose of this study was to explore sibling relationships in families of children with ASD. Qualitative research methods allows for exploration into topics where little empirical knowledge and understanding currently exist (Bogdan & Biklen, 1998; Creswell, 1994; Lincoln & Guba, 1985). Thus, given the gaps in existing literature on sibling relationships in F-ASD, a deeper understanding of the scope of the issue is necessary. As a first step, qualitative methodology was used in order to engage in an in-depth exploration of the nature, quality, and perspectives on sibling relationships in F-ASD. Qualitative approaches are especially pertinent when systematic, rigorous, yet naturalistic data collection is needed in order to understand the fullness of the experience under study (Bogdan & Biklen, 1998). Personal circumstances are explored through processes such as observations and personal narratives or interviews. The findings that emerge from qualitative research are based not only from the information shared by each individual, but also from the interpretation imposed by the researcher. Such interpretation is influenced by the researcher's own values, attitudes, and experience (Isaac & Michael, 1997; Strauss & Corbin, 1998). Distinct from quantitative methodology, qualitative inquiry is not based on pre-established hypotheses or a supposition of outcome statements of directionality or causality (Isaac & Michael, 1997). In contrast to quantitative research, qualitative research provides greater understanding of a phenomenon, through the development of themes, from the primary data source/experts of the issue

at hand—the people themselves (Bogdan & Biklen, 1998; Lincoln & Guba, 1985). The researcher herself serves as a secondary data source through her naturalistic observations and interpretations of the data.

My Role in the Community

Qualitative inquiry brings a unique set of issues to consider during each step of the research process. One point of consideration is the researcher's positioning with the participants (Emerson, 1983). In addition to being a researcher, I am a community-based, licensed clinician serving children with ASD and their families. I have over 10 years of experience working with children with ASD, providing intervention services such as individual counseling and social skills groups. I also provide support services to family members of children with ASD, such as parent and sibling support groups. As such, I entered into this investigation with both personal and professional experiences and perspectives about this population.

Drawing on Daly (2007) and May and Pattillo-McCoy (2000), I recognized that potential families identified through recruitment activities might have had pre-existing knowledge of my role in the community, which could be an unspoken influence on them to participate. Given the small community of families with children with ASD (particularly within the counties of interest for this study), I was also aware that it was possible that families with whom I have/had familiarity or expected to in the future may express interest in the study for various reasons. This was a particular issue of sensitivity as I did not want to unknowingly suggest or influence them to have any expectations about future interactions with me as a clinician, anticipate a potential benefit to them at a later point in time by participating, or feel obligated to participate in this study based on a pre-established relationship. Thus, I specifically did not seek out any families with whom I already had a professional connection. In order to establish appropriate boundaries with participants, I informed

all families (both those selected and not selected) of my dual role; clearly defining my role with them as researcher versus clinician. Additionally, I proactively informed participants that their decision to participate and/or decline participation in this study would have no bearing on any future relationship I may have with them in another role. Moreover, families were informed that this dissertation research was being conducted independent of my affiliation with any private or community agencies.

As a clinician with an expertise in ASD, I recognized that I might observe family interactions that could be helped through clinical intervention or psycho-education. Likewise, with knowledge of my professional background, I was aware that some families might request feedback or support. I proactively informed all participant families that, for this study, my role did not include providing any clinical interventions such as professional feedback, opinions, or guidance (this excludes any mandated reporting requirements such as at-risk behaviors or incidents requiring Child Protective Service notification). In an attempt to maintain neutrality and fidelity, in part, to Daly's (2007) notion of *dynamic objectivity* (trying to balance not getting too close, while not seeming too distant), I made every effort to select families who had no or limited previous interactions with me in the community. Similarly, I informed all study participants that if they had specific concerns related to their children, but not directly related to the study activities, I would provide them with resources for support. At the conclusion of the data collection and analysis, all study families were provided with an ASD/disability resource packet, developed by me, as a token of appreciation for their participation.

Research Questions

This qualitative inquiry was motivated by the current research around families of children with disabilities, in particular ASD. This existing knowledge on this topic allowed for general research questions to be posed helping focus the data collection and analysis. While the initial

research questions remained unchanged during the process, the emerging themes and related findings naturally refined the questions in the end. In this study, three main research questions guided the investigation:

- 1. What is the nature of sibling interactions in families of young children with ASD?**
- 2. How do family attitudes and beliefs about ASD have an influence on sibling relationships?**
- 3. What factors contribute to parental decisions to access sibling support services?**

Using a qualitative approach, I conducted detailed observations and interviews that provided a rich data source for exploring this issue.

Procedures

Based on the phenomena of interest, the unique experiences, and the narrow focus of this study, purposive sampling was employed. Although purposeful sampling limited the pool of subjects, it was necessary in order to have a more appropriate and purposeful sample. Common to in-depth, exploratory studies, a small number of target families were recruited to learn about sibling relationships in F-ASD (Bogdan & Biklen, 1998). The purpose of the small number of cases was to allow for a deep exploration of family experiences and stories that might help me to understand the dynamics involved in sibling relationships. In order to understand the breadth of experiences with this unique population, multiple insights were needed. As such, the issue of saturation was relevant in this situation. ***Saturation*** is essentially the continuance of sampling and data collection until no new insights are produced. In other words, data saturation occurs when the researcher is no longer hearing or seeing new information (Bogdan & Biklen, 1998; Morse, 1995). Thus, I sought to recruit additional participants above and beyond the target families in order to hear multiple perspectives about these sibling relationships. This sampling strategy was engaged to select

families with similar, yet unique, family situations that could provide rich and diverse information on this topic. Siblings with and without ASD, parents, and clinical professionals were identified as key informants in order to gain multiple perspectives (see Table 1).

Table 1

Participant Overview

Participant Group	Type of Data Collection
Target Families:	Observations of sibling interactions and in-depth interviews of family members
Focus Groups:	<ul style="list-style-type: none"> • Interview with a parent focus group • Interview with a typically developing sibling focus group
Professionals:	Questionnaire related to F-ASD sibling relationships and family support needs.

Definition and Identification of Target Population

Autism spectrum disorder is a broad term used to describe children who could have any of these three diagnoses in the current DSM IV-R (APA, 2000): autism, Asperger’s Syndrome, or PDD NOS. For the siblings diagnosed with ASD, I specifically recruited children considered to be “high functioning” along the ASD continuum. For the purpose of this study, “high functioning” was defined as a child having age appropriate verbal/language *ability* (although not necessarily age appropriate *use* of language—i.e., pragmatic language abilities). These children have a cognitive/intellectual ability likely deemed in the average to above average range (excluding any specific mild learning disabilities that may be present). Based on this definition, the children had a diagnosis of Asperger’s Syndrome or “high functioning” autism/PDD NOS. These criteria were evidenced by a formal diagnosis given by a certified professional such as a psychiatrist, psychologist or developmental pediatrician. Although it was not required for selection (parental verbal confirmation of diagnosis was requested), families were asked to provide diagnostic

documentation (i.e., copy of selected portions of an evaluation, copy of relevant sections of an IEP, etc.). Confidentiality of medical records was assured, to the best extent possible, to all families. All families willingly provided this information and this request did not deter the desire to participate in the study.

Additional family selection criteria were instituted in order to obtain the desired sample. First, I sought out families where there was at least one child with a diagnosis of ASD and at least one typically developing child. Second, a targeted age criteria, elementary through early middle-school aged, was implemented based on the research questions and the type of involvement needed from the target children. Both the sibling with and without ASD needed to be able to clearly articulate their thoughts and feelings. A third level of parameters was instituted in order to obtain a productive age matching of siblings. I recruited sibling pairs with a 2 to 4 year age difference between one another. This age range is supported by findings from the sibling literature suggesting siblings who are of a similar age are more likely to spend a significant amount of childhood experiences with one another (Dunn, 1983; Dunn, 2007; Kluger, 2011). Within this 2-4 year age range, I identified minimum and maximum ages for the siblings: minimum age of 4 years - typically developing sibling; 5 years – sibling with ASD, and a maximum of 12 years for either the sibling with or without ASD. Examples of how the age rules applied are as follows:

- If the typically developing sibling is 4 years old (minimal age required), then the sibling with ASD must be at least 6 years old and no older than 8 years old.
- If the typically developing sibling is 10 years old, then the sibling with ASD must be at least 6 years old and no older than 12 years old.
- If the sibling with ASD is 5 years old (minimal age required), then the typically developing sibling must be at least 7 years old and no older than 9 years old.

- If the sibling with ASD is 11 years old, then the typically developing sibling must be at least 7 years old and no older than 9 years old.

Due to the limited pool of eligible participants, this age rule was suspended for two cases that will be discussed in more detail in subsequent sections. There is research to suggest that young children (as young as preschoolers) can be primary and active participants in research from interviews and focus groups to observations (Fine & Sandstrom, 1998; Graue & Walsh, 1998; Greene & Hogan, 2005; Greig & Taylor, 1999; Hatch, 2007; Holmes, 1998). Even though children as young as four years old have been found to demonstrate interest and age expected understanding of the research process (McKechnie, 2000), and thus be engaged and contribute to the study, feedback from adults/parents was also obtained as secondary data sources.

Due to the in-depth exploration of sibling experiences, I aimed to recruit a small number of primary families. Common to qualitative research (Creswell, 1994; Morse, 2000; Spradley, 1980), this small, select group of participants allowed for a deeper level of immersion into the lives of these families, in order to obtain a greater level of understanding of their experience. Siblings were also recruited to participate in a one-time focus group as a means of gathering additional perspectives about sibling relationships in F-ASD. As noted earlier, appreciation of primary/target family participation was demonstrated through the distribution of a notebook/packet with information and community resources related ASD and other developmental disabilities.

Participant Recruitment

Sampling Source

Participants were drawn from the suburbs of a major metropolitan area in the Northeastern United States. Given the unique population of interest, the targeted recruitment sources were those specifically connected with children with ASD and/or their families. Three main types of

recruitment sources were identified: 1) schools serving children with ASD; 2) agencies/organizations/professionals serving children with ASD and their families (including those providing diagnostic and other intervention services); and 3) agencies/organizations/professionals serving siblings of children with disabilities. The types of supports and services these sources represent included:

- Mental health supports (i.e., individual therapy, family therapy, social skills group, psychiatric services, etc.)
- Support groups (e.g., sibling support services, parent support groups, etc.)
- Educational services (i.e., special education programming and services)
- Information, referral, and advocacy (i.e., providing education on community resources and linking families to resources)
- Therapeutic and recreational programming (e.g., social clubs, summer camps, weekend programs, etc.)

As a professional in the community, I have familiarity with professionals, agencies, and community resources serving this population which helped to focus the initial recruitment efforts. My first recruitment activities involved the dual purposes of targeting potential professional participants, and utilizing my pre-existing relationships with these community professionals to provide assistance with recruiting the target families and other study participants.

Sampling Strategy and other Recruitment Activities

Prior to starting any recruitment activities, approval from the university's institutional review board was sought and received. As noted earlier, purposeful sampling was utilized for recruitment. Purposeful sampling has been identified as a beneficial and advantageous strategy in qualitative research (Patton, 1990). Of the sixteen types of purposeful sampling, three were

employed for this study: criterion, homogenous and snowball. **Criterion** sampling requires that certain conditions are established for participant selection. Specific to this study, the criteria established revolved around diagnosis, verbal ability of the children, and sibling ages.

Homogeneous sampling involves the selection of a small number of participants with similar characteristics (based on the phenomena of interest). This type of sampling is particularly worthwhile for investigating a group of individuals in-depth. As the criteria were set forth, a fairly homogeneous group of primary target families was obtained—those with children with a diagnosis of Asperger’s Syndrome or PDD NOS. Furthermore, they shared other similar characteristics such as: two-parent households, living in communities with similar community resources, and being of similar socio-economic and cultural backgrounds. **Snowball** sampling utilizes established relationships to aid in recruitment efforts. Snowballing was utilized with many of the professional participants and community organizations. As professionals were contacted to either explore participation and/or inform about the study, they helped to identify and/or contact additional professionals and community organizations. Likewise, many of the community professionals/organizations helped spread the word about the study by posting flyers, posting the study information on online listservs, and providing the flyers (see Appendix A) at various disability related events. Through this snowball process, as the first contacts were made, additional referrals to other organizations/professionals and families occurred, resulting in attaining the select group of participant families.

Contacting potential recruitment sources was done as a two-tiered process. The first tier involved personally contacting (via phone or email) professionals with whom I had a prior professional relationship. These professionals included psychiatrists, developmental pediatricians, speech therapists, mental health professionals/therapists, social service-related agency contacts, and

private schools for children with ASD and related disorders. During this exchange, they were informed of the study topic, the rationale for the study, and the three main research questions. A brief description of the desired inclusion criteria for families/siblings was also provided. For those contacted by email, an electronic copy of both the study flyer and overview was given for their review and dissemination (see Appendix A). A follow-up phone call and/or subsequent emails were done with those who positively replied to the initial email. Additional paper copies of the fliers were given to these sources at their request. For the sources contacted by phone, a verbal description of the study was provided and a follow-up email (identical to the others) was sent as a summary to the phone call. As requested, a copy of the IRB approval notice was provided. The snowballing process occurred naturally during this phase, which led to the second tier of recruitment. Several of the 1st-tier sources provided referrals/recommendations for the next layer of contacts. Some of the 1st-tier sources offered to contact these organizations/professionals directly, while others gave names of targeted referrals. As part of the snowballing effect, many of these sources also offered to inform specific families about the study.

Due to the specificity of this study with regards to the population of interest and the selection criteria, recruiting participants was a challenge. Three main predicaments were encountered: 1) several families expressed interest in the study, however the verbal ability of their child with ASD did not meet the criteria; 2) the age span between siblings was too wide to be included in the study; and 3) families with whom the researcher had significant previous/current contact were not a desired group of participants. As a result of all of these factors, in addition to the typical recruitment process and related dilemmas, a final combination of a criterion-based yet convenience sample (both for target and focus group families) was identified. Details of the selection process is discussed in the next section.

Professional participants. As noted, for the recruitment of professional participants, I drew heavily from my personal and professional contacts in the community of clinicians serving children with ASD and their families, specifically those with experience in providing sibling support services. Five professional participants were recruited through this personal contact. As these initial phone and email contacts were made, I inquired about any additional recommendations for and/or assistance with recruiting potential professional participants. As a result of this approach, two additional participants were recommended, contacted, and secured as the final two professional participants. Coincidentally, I had had prior contact with one of the professional participants recommended. The other of these recommendations led to the securement of a trailblazer in the field of sibling support services for siblings of children with disabilities. I specifically selected professionals to contact based on prior knowledge about their role in the community and their level of contact with families of children with ASD. Thus, as the professionals expressed interest and accepted participation in the study, they were automatically selected as participants.

The first step in the recruitment of professional participants coincided with contacting recruitment sources, as the professional participants served dual roles. Due to the schedules of the professionals, much of the recruitment communication occurred via email. Similar to the exchanges with recruitment sources, the professional participants were sent an email informing them of the study and providing a brief overview of the purpose of the study and study methodology. A PDF copy of the study advertisement was attached to every email for their review. All of these participants, except for one (who was out of state and preferred to communicate via email) received a follow-up phone call (s) from me to discuss the study in more detail. During this phone call an explanation of the IRB approval process and the consent process was explained. Each participant was then sent a follow-up email in which a PDF of the consent form was attached. They were

asked to review, sign, and return the consent form (via fax, scan, mail, or in person). Upon receipt of the consent forms, these participants were then provided a questionnaire via email (see Appendix B).

Target family and focus group participants. The early recruitment of target and focus group families occurred simultaneously. The determination of which participant group (target family or focus group) each family would be assigned occurred during the selection phase. Families were initially informed of the study through their contacts with the recruitment sources: agencies, organizations, professional groups, schools, and community professionals (i.e., case workers, therapists, developmental pediatricians, and psychiatrists), school newsletters, community parent meetings, internet listservs, and the like. Due to confidentiality issues and the sources from which families heard about the study, all opening contact with me was initiated by the family. Many families introduced themselves by email and expressed an interest in learning more about the study. These families were given a prompt reply email which included a detailed overview of the study. PDF copies of the study flyer and overview were also attached to these emails. Additionally, I indicated that I would make a follow-up phone call with them if there was continued interest in the study. These follow-up phone calls, along with any additional information provided in their initial email to me, began the selection process as described below.

The recruitment of focus group participants continued beyond the selection of the target families based on the timing of focus group activities. Several families learned of the study after the target families had been selected and data collection begun. However, as new families made contact, the same recruitment processes were followed as described above, although these later families were informed that they would be considered for participation as focus group families only.

Participant Selection

Sixteen (16) parents responded to the recruitment advertisement or verbal notification of the study. All of these participants indicated that they would be willing to participate as either target and/or focus group families. During the initial email and/or phone contact, three (3) families self-eliminated participation (as potential target families) based on the criteria set forth. The main factor was the verbal ability (and on occasion, functioning level) of their child with ASD. All of these families, however, expressed an interest in participating, in any way possible, at my discretion. At the prompting of a recruitment source, I directly contacted an additional family. The recruitment source got permission from the mother to have me make the initial contact. Two calls were made to the family, however, there was no response to the voicemails and no further attempts were made. One of the 16 families expressed interest in the study but did not return phone calls or respond to follow-up emails after the initial contact. Two of the 16 families were eventually eliminated as study participants due to either 1) location of residence (over 1 hour distance), or 2) age difference of the child who would participate in the focus group. Of the 16 families that expressed an interest in the study, a final ten (10) met the inclusion criteria and indicated continued interest in the study. One of the ten families interested in the study was one with whom I had a prior acquaintanceship. This family learned about the study from community recruitment efforts and not any direct solicitation from me. In order to assess any possible ethical boundary issues in working with this family, I sought out consultation from various sources (i.e., clinicians in the field autism, other community therapists, university mentors/advisor, etc.) in addition to speaking with the family directly about the possible conflicts. After careful consideration of any negative outcomes, it was agreed that the family could participate in select aspects of the study, specifically the focus groups, with members of the family with whom I had more limited previous contact (i.e., the typically

developing sibling and the mother). After all recruitment and selection activities were completed, a total of four (4) families were selected as target families and an additional five (5) families were selected as focus group families. Details of the final selection of participants are presented below.

Screening and confirmation of participant families. Due to the complexity of ASD, participant selection was a multi-step process. To ensure that the diagnostic label given to the child and the selection criteria for this study were congruent, both phone screenings and face-to-face meetings with families were conducted as part of the selection of study participants. This two-step process was particularly important as the diagnostic criteria for ASD, especially that of PDD- NOS and/or [high functioning] autism (APA, 2000) are less definitive with regards to functioning level. Likewise, parent report of a child's functioning level and abilities is subjective by nature.

As noted above, most families/parents initiated contact via email. For those who made email contact, a reply email was sent thanking them for their interest. They were provided with a copy of the study advertisement, as some may have learned of the study without seeing the flyer. A brief description of the purpose of the study was also included in that email, along with a request to contact them via phone if they continued to be interested in learning more about the study. For those families who requested further contact, a follow-up phone call was made, during which time I provided parents with a brief overview of the process of the study (e.g., in-home sibling observations, family interviews, focus groups, consent process, etc.). I also noted that their participation in the study was completely voluntary and would have no bearing on any possible future professional contact with me in my professional (vs. researcher) capacity. Several of the families had peripheral knowledge of me through my role in the community as a clinician working with children with ASD.

During this phone conversation, information about the family, sibling constellation, diagnostic history of the child with ASD, etc. was obtained using a screening form (see Appendix A). These phone screenings served as the primary means of early participant identification (meeting the basic selection criteria per parent report). Based on this screening, I determined which families seemed most appropriate to be a target family and which should be reserved as a focus group family. This determination was made during the time of the screening phone call. Families whose child with ASD was described as having moderate verbal abilities, but met all other selection criteria, were reserved for future consideration as a focus group family. These families were told that they would most likely be appropriate for the focus groups and would be contacted at a later time with more information when focus group planning took place. For those families who met the basic selection criteria (for target family selection) but could not be a target family due to the time commitment, focus group participation was also discussed. For families who seemed appropriate for consideration as target families and were interested in this level of participation, they were informed that a final face-to-face meeting needed to be held for final decision (see Appendix C).

Follow-up home visits. Initial home visits were arranged for the four families identified as potential target families. This meeting served to: 1) confirm that the child with ASD met the necessary cognitive/intellectual functioning and verbal skills needed for this study, and 2) review the study procedures and obtain written consent and basic family demographic information (see Appendix D). Prior to the home visit, families were informed of and provided with the consent forms, the child assent script, and the HIPPA form (via mail or PDF version through email) for their review. At the home visit, a verbal overview of the study was given to the parents, including an estimate of the time commitment needed by each family. Parents were told that participation was voluntary, that they could choose to withdraw from the study at any time, and that all personal

identifying information about them or shared by them during the study would be kept strictly confidential. I discussed the use of audiotapes during family interviews and that they would be transcribed, that pseudonyms would be given to all participants, and that the tapes would be destroyed at the completion of the dissertation project and related activities. Upon receiving their verbal agreement to this commitment, the paperwork was verbally reviewed and parents signed all needed documentation. A family demographic questionnaire was presented and completed during this visit as well. This initial paperwork was completed without the children's participation.

After parents signed the consent forms and related documents, the children were invited to join the meeting. It was at this time that I engaged with the children and provided a verbal overview of the study (see child assent script- Appendix E). To confirm understanding of the study and their participation, the children were asked to verbally tell me what they understood about the study and what I would be doing with their family. Upon confirming age-appropriate understanding, children were asked if they wanted to participate in the study. Verbal affirmatives were received from all children. Two families had the children sign the child assent script, although this was not a requirement. All of the four families were found to be appropriate target families.

Final selection of focus group families. The purpose of the focus groups was to gather additional family perspectives on the issue of sibling relationships in F-ASD. The goal was to have three distinct focus groups: 1) children with ASD; 2) typically developing siblings of children with ASD; and 3) parents of these siblings. Final decisions about focus group participants occurred towards the end of the data collection process for the target families, allowing "second wave recruitment families" to be considered (of the 16 mentioned). Several factors went into the decision of the focus group(s) composition, with various options were under deliberation:

- a. Focus groups comprised of a combination of target and non-target families.

Combining of both target family and “new” or non-target families could allow for a rich sharing of experiences. This option would allow for comparisons of experience between families with whom I had more intimate contact (target families) and those with whom there was very little contact. This mixed group could also allow new experiences to be mentioned and trigger additional insights to be shared by the target families as a result of the interplay of group dynamics. This could also help me explore differences between what the target families reported when interviewed individually vs. in a group setting.

- b. Focus groups with only non-target “new” families. This option would allow for new insights to be shared by a separate group of families to also be compared to the target families, but as a totally separate group of participants. This would allow for comparisons to be made between participant groups based on the information shared during their separate data collection processes and without the influence of either group on their responses.
- c. Target families only focus groups. Similar to the mixed-group, this option would allow for additional information to be shared by the target families, triggered by the experiences shared by the other target families. This would also allow for me to discover differences between what the target families reported when interviewed individually vs. in a group setting. It would not allow for a comparison of experiences with other non-target families.

The options were discussed with my mentor and dissertation committee members. Additional perspectives were obtained from dissertation committee members as well as outside professionals in

the field of disabilities. All options presented rich information, and one did not appear more attractive than another. Final decisions about the composition of the focus groups were made, in part, due to convenience, but also jointly in careful consideration of the rationale for each option.

Concentrated consideration of focus group participants occurred via reviewing the family demographics from “first wave recruitment families” reserved for focus group consideration and “second wave” families. Target families were also informed about the focus groups and invited to be considered for participation. Participant burden, unexpected events, and scheduling challenges significantly limited the participation of target families for the focus groups (two families declined participation; one family had very limited time availability; one family indicated willingness to participate in all aspects of the focus groups). As family availability (days/times) for the groups were obtained, one of the target families was eliminated, leaving only one target family as potential focus group members. Given the unbalanced nature of target vs. non-target family participants (TF and FG family ratio), I opted to not have any target families participate.

A total of seven (7) non-target families were considered for the focus groups. Ideally, each family would have been able to participate in all three types of focus groups and group composition would have had children of similar age. However, only three (3) of these families had children with reported diagnoses of Asperger’s Syndrome or High Functioning autism. The other families had children on the spectrum with reported diagnosis of autism or PDD NOS with limited verbal or conversational abilities. For the latter families, only their typically developing children were considered for the focus group (along with the parents). The final selection of focus group participants included five (5) families. Scheduling conflicts eliminated two (2) families. Another family was expected to participate but did not show up on the day of the group. Thus, three (3) families were considered for the focus groups. Only the parents and typically developing children

participated in these focus groups for two reasons: 1) two families had children with autism with limited conversational skills, and 2) I had prior familiarity with the HF autism ASD sibling(s) of the other family which did not allow for them to participate. Despite an aggressive recruitment effort, an ASD focus group was not able to be formed.

All focus group families were provided the following documents to review and sign prior to or at the date of the focus group: copy of the study flyer and overview of the study, consent forms, HIPAA form, child assent script, and a screening form modeled after the phone screening form (see Appendix A). To maintain consistency with confirming diagnoses, parents were asked to provide documentation of the ASD diagnosis of their child even if not directly participating in a focus group.

Participants

This section provides a description of the primary study participants (target families). Descriptions of the other key informants of the study: community professionals and focus group families are also presented. Due to the sensitive nature of the diagnoses represented in this study and the intimate details of family life shared, identifying information has been changed (i.e., the use of pseudonyms) in order to protect participant confidentiality.

There were a total of fourteen participants (7 professionals; 4 target families; 3 focus group families). Of the seven families, five were Caucasian and two were African-American (focus group families). While the goal of this study was to get multiple perspectives, it was not my intent to do representative sampling. Thus, it was not an issue that there was a lack of cultural and economic diversity within and between the target and focus group families. Descriptions of the participants are listed in Tables 2-4. A more detailed overview of the target families is also provided.

Professional Participants

The professionals included: social workers, professional counselors, mental health professionals, family support workers, and experts in sibling support services. Collectively, the professionals served individuals with ASD across the lifespan (see Table 2). Six of the seven professionals were either currently or previously connected with agencies that provide services to children with ASD and their families (including case management and family support services). Three of the seven professionals also provide mental health services (e.g., individual therapy, family therapy, social skills group therapy) to individuals with ASD and their families. All seven of the professionals currently or previously provided support services to siblings of children with ASD (either via 1:1 individual therapy or through sibling support groups). Six of the professionals practice in the same metropolitan area from which the family participants were selected, while the seventh was out of the Northwest area of the United States.

Table 2

Professional Participant Information

	Professional role	Type of Community Support Services Provided				
		Individual therapy for children with ASD	Individual therapy for siblings of children with ASD	Therapeutic groups for children with ASD	Therapeutic groups for siblings of children with ASD (including Sibling Support Workshops)	Family support services
Professional 1 (P1)	Professional Counselor	x	x	x	x	x
Professional 2 (P2)	Clinical Social Worker	x	x	x		x
Professional 3 (P3)	Family support services worker				x	x
Professional 4 (P4)	Family support services worker				x	x
Professional 5 (P5)	Clinical social worker	x	x	x	x	x
Professional 6 (P6)	Family support worker				x	x
Professional 7 (P7)	Author and founder of a curriculum-based sibling support program				x	

Focus Groups

There were two different focus group participants: 1) a group of typically developing siblings; and 2) a group of parents of children with ASD (and parents of the typically developing focus group siblings). All of the families lived in the same county and had received a similar level of community support services: diagnosis of their child with ASD, parent education around the diagnosis, and special education and other related therapeutic services (i.e., social skills therapy,

individual therapy, speech and language therapy, occupational therapy, etc.) for the child with ASD. Although this was not directly asked of the focus group families, during the course of the interview, two families openly shared that they have a religious affiliation (Catholic and/or Protestant). All of the families were a two-parent household (mother and father) with only one typically developing child. All but one family had only child with a diagnosis of ASD. The third family had triplets all with ASD. Interestingly (and unique based on the statistics on the gender ratio of 1:4 that favors boys for the diagnosis of ASD (CDC, 2012)), the focus group participants represented two girls with a diagnosis of autism. Demographics of these participants are in Table 3.

The typically developing sibling focus group (FG-TD)⁷ was comprised of three children. At the time the focus group was held, these children were between 8 and 16 years old. The younger two boys were younger siblings of girls with autism. The oldest boy in the group was the older brother of triplets with HF autism. The parent focus group (FG-P) included four (4) parents: 3 mothers and 1 father (two parents were a couple).

Table 3

Focus Group Participant Information

	Parent(s)	ASD Child	Diagnosis	Age of ASD child	TD child(ren)	Age of TD child(ren)
Family 1	Diane	Daniel Mark James	HF Autism	12	Charlie	16
Family 2	Victoria	Emma	Autism	9	Paul	8
Family 3	Rhonda and Calvin	Cindy	Autism	9	Sean	8

Target Family Participants

⁷ The abbreviations will be used: Typically developing siblings (TD-S), Siblings with ASD (ASD-S), Target families children and parents (TF-TD or TF-ASD or TF-P), and Focus group (FG-TD or FG-P).

There were a total of 4 target families. Within these families, there were 3 boys and 1 girl with ASD. The diagnoses included Asperger's Syndrome and PDD NOS. Their ages ranged from 6-10. Between the 4 children with ASD, there were 6 typically developing siblings: 5 boys and 1 girl. Their ages ranged from 6-12. A more detailed description of each target family is provided below (see Table 4).

Target Family 1: The Smiths. The Smith family is a family of four. Barbara Smith is currently a stay-at-home mother while Sylvester Smith is a lawyer. They have 6 year-old twin boys named Zachary (TD-S) and Blake (ASD-S). The family lives in a middle/upper-middle class suburb in a single family home. Blake is diagnosed with PDD NOS and is receiving special education services from the public school system. He also receives other related services (i.e. speech and OT) both through the school system as well as through a private provider. Blake has many of the characteristic symptoms of ASD, including poor social understanding, perseverative behaviors often related to his intense interest in dinosaurs, and difficulty with impulse control. Blake is a very verbal child on the autism spectrum, although some of his language has an echolalic quality to it. Mr. and Mrs. Smith describe Zachary as a very social little boy, and one who craves adult attention. Zachary is not reported to have any suspected disabilities or delays. He attends a different school than his brother.

Target Family 2: The Johnsons. The Johnson family includes Frank and Linda and their four children: Thomas (12 years old), Kimberly (ASD-S, 10 years old), Jennifer (TD-S, 8 years old), and Louis (5 years old). They live in a middle-class suburb in a single family home. Both Mr. and Mrs. Johnson work outside the home; Mr. Johnson (lawyer), Mrs. Johnson (statistician). Kimberly has a diagnosis of PDD NOS but would be classified as a high functioning child on the spectrum. Kimberly receives special education services from her public school system. Kimberly

is described (and observed) to have a few of the qualities characteristic of ASD: self-stimming behavior (i.e., hand flapping or leg slapping when excited) and poor emotion-regulation. Mrs. Johnson indicated that while not receiving any special services at this point, the two youngest children had some speech delays when they were younger. Kimberly and Jennifer are reported to have a different sibling connection with each other than they do with their other siblings. Mrs. Johnson reported that the two girls are very close, but also experience the most sibling conflict.

Target Family 3: The Taylors. The Taylor family is a family of four. Karen and Mike Taylor have two sons: Christopher (ASD-S, 9 years old) and Daniel (TD-S, 7 ½ years old). They live in a single-family home in a middle-class, suburban neighborhood. Christopher has a diagnosis of PDD NOS. He displays many of the hallmark symptoms of ASD: stimming behaviors, perseverative or repetitive conversations, intense interests (i.e., music), and difficulty understanding social cues. Irrespective of the diagnosis, Christopher is described as a very social child, whom many adults and children adore. Christopher is in a special education program through his public school system in a middle-class suburb. Daniel is described as an athletic and friendly child. He is described to be not as outgoing and extroverted as his older brother, Christopher. Both Mr. and Mrs. Taylor are working parents. Mrs. Taylor works for a public school system, and Mr. Taylor is in architectural drafting.

Target Family 4: The Andersons. The Anderson family includes Jane and Richard and their two sons: Kevin (ASD-S, 11 years old) and Greg (TD-S, 8 1/2 / 9 years old). They live in a middle-class neighborhood in a semi-suburban neighborhood. Kevin is diagnosed with Asperger's Syndrome and is reported to be extremely bright. Jane and Richard describe their sons as having a difficult period of sibling conflict a few years ago. Conflict is still present in their sibling relationship, but reportedly much less than it was before. Mr. and Mrs. Anderson describe Greg as a

“social-butterfly” who is very athletic. Greg is also described as being very competitive. Kevin, on the other hand, is described as very smart and with various gifts (e.g., musical ability). Kevin receives special education services through the public school system and also participates in private social skills intervention with his long-standing therapist. Mrs. Anderson works for the local public school system and Mr. Anderson is a business owner.

Table 4

Target Family Participant Information

	Parent(s)	ASD Child	Diagnosis	Age of ASD child	TD child(ren)	Age of TD child(ren)
Target family 1	Barbara Sylvester	Blake	PDD NOS	6	Zachary	6
Target family 2	Linda Frank	Kimberly	PDD NOS	10	Thomas Jennifer Louis	12 8 5
Target family 3	Karen Mike	Christopher	PDD NOS	9	Daniel	7 ½
Target family 4	Jane Richard	Kevin	Asperger's Syndrome	11	Greg	8 ½ /9

Informed Consent

Both written and verbal consent/assent was obtained and reviewed multiple times throughout the data collection process. Following Internal Review Board (IRB) requirements, written informed consent was obtained from all adult participants. All of the target and focus group families were from two-parent households, and in most cases both parents were present during the signing of the consent forms (target families) and/or where included in the dissemination of the consent forms (focus group families). As long as one parent/legal guardian agreed to participate, their consent was accepted.

As noted earlier, during the signing of the consent forms (and verbal assent from children), participants were informed that they could choose to withdraw from the study at any time without consequence, and that all identifying information about them or shared by them during the study would be kept strictly confidential. Parents were asked for permission to audio-record family interviews with them and their children. While this was noted in the written consent, verbal consent was also obtained. Parents were told that these recordings would be listened to and transcribed only by me and the principal researcher/university advisor. In addition, all participants, especially parents were assured that pseudonyms would be given to all participants and that all transcript contents and other personal information would be kept secure and confidential. Participants were also encouraged to contact the researcher at any point during or after the data collection if they had any questions or concerns. All focus group consent forms were signed and received prior to their child's participation in the study.

Following this description of the participants is the discussion of coding processes and the outcomes of the data analysis that supported the resulting themes that emerged.

Methods of Data Collection

Data collection for this study involved an integrated and complementary set of activities which resulted in the accumulation of a depth and richness of information about this particular area of interest. Data sources for the current study were three types: 1) a professional questionnaire; 2) in-depth in-home sibling observations; and 3) interviews with families of children with ASD (target family and focus groups).

Details of each of the data collection methods are described in the following section, mindful of their context within the research questions. The research questions bring focus to the methodology, including the selection of participants, data collection, and the process of data

analysis (Bogdan & Biklen, 1998; Miles & Huberman, 1994). Specific procedures were utilized to address each particular research question (See Table 5). The entire data collection process occurred over a 6 month period of time.

Table 5

Data Collection Procedures

Research Question	Procedure	Sequence of Procedures
RQ1: What is the nature of sibling interactions in families of young children with ASD?	<ul style="list-style-type: none"> • Observations of sibling interactions (primary) • Parent interviews (target families and focus group) • Sibling interviews (target families and focus group) 	<p style="text-align: center;"> Professional Questionnaires ↓ Observations ↓ Interviews-Target families ↓ Additional Observations ↓ Focus Groups </p>
RQ2: Do family attitudes and beliefs about ASD have an influence on sibling relationships?	<ul style="list-style-type: none"> • Professional Questionnaires • Parent interviews (target families and focus group) • Sibling interviews (target families and focus group) 	
RQ3: What factors contribute to parental decisions to access sibling support services?	<ul style="list-style-type: none"> • Professional Questionnaires • Parent interviews (target families and focus group) 	

Professional Questionnaires

The completion of the professional questionnaires was the first step in the data collection process. Not only were these participants secured early, but their feedback was fundamental to informing certain questions to be asked during the family interviews/ focus groups and helped to provide context to the observations of sibling (and parent) interactions. The purpose of the questionnaire was to gather information about what these professionals have experienced to be key issues related to sibling relationships in families of children with ASD based on their direct and intimate work with this population.

The consent process and the data collection process occurred simultaneously. As each of the seven professionals provided verbal/written email agreement to participate, they were given both a written and verbal description of the study rationale as well as an overview of the overall methodology for all aspects of the study. The written consent process was explained to each professional and they were given a copy of the consent form via email/mail/in-person to review, ask questions, sign and return. Upon receiving both the verbal and written consent to participate, all of the professionals were provided the questionnaire via email to complete at their convenience. Two of the professionals returned the questionnaires via email scan or fax. Another two of the professionals hand-delivered their questionnaires, although one of the two also requested to have a face-to-face meeting to verbally discuss her responses for clarification. Two additional professionals opted to meet in-person with me to complete the questionnaire. They requested to respond to the questions verbally while I either typed their responses and/or handwrote the responses (to be later typed verbatim). The final professional participant lived in a different state, and was recommended as a potential participant by one of the other professionals (they conduct similar sibling support services--a branded curriculum on sibling support programming). This professional indicated his preference to complete the questionnaire by phone, also verbally

responding to the questions while I transcribed. All written materials were stored in a locked file cabinet, and all computer files were password protected. Each of these participants was encouraged to contact me at any time before or after the completion of the questionnaire with any questions.

I asked a select number of the professionals if they would be available for any follow-up questions or feedback as the data collection, with the other study participants, progressed. This step served as another layer of triangulation.

Initial Screening Meetings with Target Families

The initial face-to-face screening meeting with families was not a formal part of the data collection process. However, unexpectedly, many families began to share unsolicited, yet relevant, information at this time. Due to the unexpected nature of this information, formal data were not collected at this time, although notes were written immediately after the meeting to capture the essence of the information presented. The type of information shared included descriptions of their children's sibling behaviors and the children's perspectives about their sibling relationships.

Target Family Sibling Observations

Observations of sibling interactions were the primary means of understanding the style and nature of interactions that occurred between siblings and the larger family unit. Observations were the first data to be collected for all but one target family. The goal was to conduct the observations on different days of the week, times of day, and family activities that were significant in the daily life of each family (e.g., transition time from camp/school to home, weekend, meal time, etc.). The choice of home observations was based on the desire to see the sibling interactions within their natural setting(s) for a "real-world" context. Four visits were initially estimated to be an optimal number of observations per family, with each observation visit lasting an average of 1-1 ½ hours. The scheduling of the observations was done at the families' convenience. Most families

completed their commitment within 6 weeks. The observations/home visits typically occurred once a week.

Following Cosaro's (1985) observation protocol with children, I attempted to identify various *interactive episodes* as the sampling unit. Interactive episodes serve as boundaries of the interactive event. However, as Cosaro notes, in more informal settings such as homes, there may not be the ease of identifying natural boundaries due to the continuous exchange of conversations. This phenomenon was experienced most often during the observations, as interactive events seemed to flow quickly and naturally from one situation to another. My role during the observations was that of "reactive" participant (Cosaro, 1985). As my goal was to not impose or interject myself into the sibling/family interactions, I tried to only respond to children's inquiries if there was a personal reaction or initiation of contact with me. Even in such instances, I tried to make these exchanges brief and marginal. I made every attempt to not enter into the interactive episodes as an active participant.

Documenting of observations. Detailed, written field notes were taken during each observation visit. Additional notes were also made after each visit, as necessary, if additional comments were made by parents (before or after the observation ended) or additional thoughts presented themselves. The observation field notes were then transcribed within two days of the observation to help maintain the integrity of the notes and capture my thoughts/impressions as close to the observation period as possible. The notes followed a format adapted from Cosaro (1985) in which different types of notes and impressions were recorded: *Observational Note (ON)*- objective descriptions and observation details; *Methodological Note (MN)*- notes on methods; *Theoretical Note (TN)*- subjective notes of insight and conceptual development; and *Personal Note/Observer*

Comment (PN)- personal reflections/feelings about the observed event. These notes were connected to specific observational content.

Saturation. The issue of data saturation was an important factor while doing the sibling observations. . As noted earlier, saturation occurs when no new information is obtained or generated. This issue of saturation was thoroughly taken into consideration in deciding upon the final number of observations done with each target family.

A predetermined number of home visits/observations were initially set. However, these numbers were established, in part, to give structure to the data collection, as well as an anticipated commitment period for the participants. Although a pre-established number was set, data saturation was an important final factor in determining the actual number of visits with each family.

An initial goal of four (4) observations was set for each family, and, indeed, this tended to be the general point of saturation. It was at the fourth observation that the children seemed to have shown much of their typical interaction patterns. This was confirmed by the parents as well. I also considered the concept of saturation in terms of the length of each observation. While the plan was to be at each home for about 1-1.5 hours per visit, the observation period was cut shorter (if saturation was achieved before the hour) or extended (if it seemed significant interaction was occurring beyond the hour time frame). A brief synopsis of the observations for each family is provided below:

Observations of sibling interactions.

Family 1: The Smiths. Four (4) observations were done as initially anticipated. This family opted for home visits to be done on weekday mornings or afternoons. Mrs. Smith is currently a stay-at-home mother, which allowed for flexibility with scheduling. Mr. Smith was not present for any of the observations due to his work schedule. However, he was present and actively

participated in the initial screening home visit with the family. The first two observations were completed within two days of each other. The third observation was done approximately 6 weeks later (due to vacations), and the fourth was done one week later. A couple of the observations occurred after summer homeschool teaching sessions, while others occurred during open/free times for the children. Examples of activities observed included outside play between the children and a structured interactive game. These children, especially the typically developing child, were quite engaging and appeared to desire to socialize with me. The child with ASD appeared to follow the lead of his brother in how to engage with me and his involvement often seemed peripheral, yet important. It was often difficult to position myself separate from the interactions between the siblings, mostly due to their attempts to bring me into their play.

Family 2: The Johnsons. The Johnsons chose weekend home visits due to their work schedules and other family commitments. The observations were done on the same day and similar time each visit. Such weekend visits permitted observations of events such as family lunch time, relaxed or down-times between siblings, and transitions from home to afternoon activities (i.e., birthday parties, play-dates, etc.). Both parents and all of the children were present for some portion of all of the observations. A total of three (3) observations were done with the Johnsons, within a month's period of time. The fourth observation was eliminated because this investigator assessed that data saturation had been achieved by the third visit. The children's type of engagement and level of involvement remained consistent over the three observations and it was evident that a fourth observation would not have yielded much different or expanded information. The parents commented early on that the children tended to have a less variable type of engagement and often watched TV or did more independent play. The decision that saturation had been achieved was made after corroborating with the parents regarding my perceptions and receiving

confirmation that what had been observed at that point was fairly typical of their family interactions.

Although the children were aware of my presence in the room during the observations, there was little interaction between the children and the investigator. While my physical proximity to the children was fairly close, they seemed quite able to quickly desensitize to my presence. There was a palpable shift at the second observation in which there were two fairly brief, yet pivotal, interactions between the children and me that helped to increase the rapport/familiarity between all parties. However, this did not seem to spill over or change the engagement style between the researcher and children in subsequent observations.

Family 3: The Taylors. Similar to the Smiths, observations with the Taylors were done on weekday afternoons. Mrs. Taylor's work schedule allowed for her to be home at this time and facilitated observation visits to be done during free times, lunch times, and as the children transitioned home from camp activities. Mr. Taylor was not able to participate in any of the study activities due to his work schedule. A total of four (4) observations were done with this family, over a 2-month period.

It was more challenging remaining a "reactive" participant with this family due to the highly social nature of the child with ASD. He not only initiated, but pursued regular and ongoing interaction with me. I attempted to minimize the interactions and/or keep them brief, however the child needed regular concrete redirection (from his mother) to disengage from me and engage with his brother or other activities. His brother, on the other hand, was more tentative with his interactions and seemed shy with the observation activities.

Family 4: The Andersons. The Anderson family was the only in which both parents were present during all of the observations. A total of four (4) observations were conducted spanning

two months. Home visits were done over the weekend due to the children's various summer activities and other family commitments. There was a richness of interactions during each observation which prompted the extension of each visit from one (1) to an average of two (2) hours. Various sibling and parent-child interactions were observed, including play-dates, family games of baseball and basketball, and overall free time between siblings. I was able to maintain more of a "reactive" observer role with this family. There was more small-talk before each observation, which may have contributed to a greater sense of comfort for the children with my presence. During the actual observation period, however, the children were able to disengage and seemed to treat my presence similar to any other guest's presence in their home.

Target Family Interviews

In addition to the sibling observations, an additional layer of insight into sibling relationships was sought from the perspectives of the direct sources—the family members. Interviews provide another rich source of information that cannot be obtained solely from observations (Bogdan & Biklen, 1998; Creswell, 1994; Daly, 2007; Lincoln & Guba, 1985; Miles & Huberman, 1994). The utilization of in-depth interviews is one of the most critical data components in qualitative research. Interviews allows for the participant to provide a personal account of their experience with the phenomenon of interest. As experts with the issue, participant interviews offer an "insider's" perspective. The narrative or conversational tone of interviews supports a comfortable sharing of personal stories that illuminates the insights shared by the participants.

It is recommended that qualitative interviews follow a semi-structured, open-ended format that allows for a natural, flexible, and fluid exchange (Bogdan & Biklen, 1998; Maxwell, 1996). While appropriate to have pre-selected questions as a guide, it is important to allow for

new topics to emerge and further exploration of those comments. Parent and sibling interviews with target families were conducted to hear, firsthand, how sibling and family interactions were described and understood. Semi-structured, open-ended questions were used during the interviews to help guide the discussion, however, I also allowed for the pursuit of other topics raised during the course of the interview. The original goal was to conduct two interviews per family per family member. These interviews were intended to take place within a certain sequence of events. Ideally, the first set of interviews per family was to occur after at least two sibling observations had been completed. The caution towards bias was a main factor to delaying the first set of family interviews. The attempt was made to reduce preconceived notions about “expected” observations between siblings that could have been shaped by information received during an interview. The second interview was to take place after the final set of observations were conducted as a way to 1) gather any additional insights from the family; and 2) to discuss initial impressions formulated by me and to check for accuracy. While the sequencing of the interviews were upheld (when possible) with the families, the second set of interviews was dropped. Saturation was the significant factor. Across all families, parents were forthcoming, early on, with information about their children’s sibling interactions. They openly and naturally shared their thoughts all throughout my contact with them. None of the families waited until the identified “interview session” to share insights and they tended to provide detailed information prior to and during the formal interview session. Bogdan and Biklen (1998) state “information in the qualitative interview is cumulative” (p. 95). With that in mind, upon completing the first round of interviews with the families (considering the thoroughness of their answers), I felt that a level of saturation had already been achieved and forcing a second interview would have been counterproductive. These mid-observation interviews,

however, helped to provide an indirect level of interpretation of the sibling interactions observed up to that point. A more detailed description of the interviews will follow in the next sections.

The interview as conversation. Due to the relational nature of the data collected, the setting of the interviews was critical. As noted for observations, the natural environment is an ideal setting for qualitative research (Isaac & Michael, 1997). Like the observations, interviews were done in the home—a place where people are typically most comfortable. Due to the personal and sensitive nature of the information shared in these interviews, establishing rapport and a warm and responsive conversational style was important.

Interviews are a process of uncovering the meaning of a person's experience. Interviews allow others to share their story from their own perspective; in their own words. The interview is a joint experience between the researcher and the participant, requiring a certain level of mutual interest and comfort in talking openly and uninhibited. Hence, a certain level of rapport is needed between the two parties (Isaac & Michael, 1997; Miles & Huberman, 1994). Much of this rapport had been established with the family members prior to the interview due to the extended engagement and time already spent doing the first set of observations. This likely increased their comfort level in sharing their experiences and stories. However, it was important to also be mindful of the dynamics of interaction occurring between me and the participant; paying attention to the question forms (i.e., introducing questions, follow-up questions, probing questions, direct and indirect questions, clarifying questions, interpreting questions, and even silence) and how both the participant and I responded and reacted through non-verbal communication. Techniques of empathic and active listening were also central to establishing a comfortable and relaxed conversational style and tone. I attempted to demonstrate behaviors which communicated genuine interest (e.g., smiling, nods of affirmation, eye contact, voice inflections etc.). I was particularly

diligent to not, however; offer any personal opinions or insights into the information shared.

Parent and sibling interviews. As mentioned earlier, the parent and sibling interviews with each target family occurred, in most cases, after at least two sibling observations were completed. The start of the interviews were postponed until after sibling observations had begun as an attempt to reduce observer bias that could be prompted by any information obtained through the interviews. Likewise, it was suspected that the early sibling observations could assist with the formulation of additional, more involved, interview questions for the family members. The format of audiotaped semi-structured interviews was used. The focus of the questions was geared to elicit information about parent and sibling perspectives on family and sibling interactions as it relates to having a child/sibling with ASD (see Appendices F and G). These predetermined questions allowed for some uniformity with the interviews and also the type of information received.

In most cases, the mothers participated in the parent interviews, although it was the desire to have both parents, in the case of two-parent households, to be interviewed. This was not possible for the majority of the families due to work schedules and the timing of the home visits and interviews. Each parent interview lasted approximately 45 minutes. In addition to gathering more information about the nature of the sibling relationships in each family, the parent interviews also allowed me to ask the parents for clarification and insight into certain sibling interactions observed. Although the second interview was eliminated, parents were invited to contact me at any point should they want to provide additional thoughts related to the interview questions.

The sibling interviews were conducted in the same data collection sequence as the parent interviews. The goal was to have separate interviews for the child with ASD and the typically developing child(ren). In instances where there were multiple children a group/joint interview was allowed, especially if this was a reflection of sibling dynamics within the family. This allowed for

an examination of and elaboration on multiple experiences within the sibling system.

Each sibling interview was held in the family's home and lasted approximately between 30-45 minutes. The interviews followed a semi-structured format, but it was especially important that the children had the opportunity to initiate impromptu conversations and for unplanned, naturally occurring questions to be presented as the conversations unfolded. Due to the age/interests of the children, and as a means of engagement, a couple of the interviews were done in conjunction with drawing, coloring, or other activity to help increase their comfort level and elicit information. With the consent of parents (and children), all of these interviews were audio recorded.

Synopsis of target family interviews. At the start of each child interview, I revisited the purpose of the study, checked for their level of understanding about their participation in the study and the interview, and obtained verbal agreement to conduct the interview. I also asked the child for permission to audio-record the conversation. As many of the children were not as familiar with the tape recorder, I allowed them to practice recording and playing back their voices. A brief overview of the family interviews is presented below.

Family 1: The Smiths. Both the TD-S and parent (mother) interviews were conducted on the same day, after the first two observations were completed. There was a six-week hiatus between the second observation and these interviews. The TD-S seemed rather comfortable with me and was not only very willing to participate in the interview, but also demonstrated a level of verbal communication skills and insight not expected of a child his age (6 years old). The interview was done while he was engaged in coloring in his coloring book and cutting out pictures. This seemed to reduce the initial apprehension he showed and also promoted continued rapport-building through the light-hearted discussions around his artwork. The ASD-S refused to participate in an interview, even after multiple attempts of encouragement from his mother. I also tried having his

mother interview him herself, at a convenient time when I was not around (giving her a set of questions to ask). This attempt was also unsuccessful.

Family 2: The Johnsons. Three separate interviews were done with this family: parent (mother) interview, TD-S interview, and a joint interview with the ASD-S and two of her siblings. The order of these interviews did not entirely comply with the pre-established schedule. The first interview, the joint sibling interview, was conducted after only one sibling observation. However, the nature of the interview permitted me to observe their sibling interactions during the conversation. The joint interview was intended to be an interview with the ASD child only. It began as an ASD-S only interview. The child was intensely involved in playing a computer game and did not want to stop. After negotiating with her she agreed to the interview if allowed to continue playing the game (with certain limitations presented). Even with the negotiated boundaries, she was able to quickly shift completely over the interview. Shortly thereafter, her sister requested to join the interview and the younger sibling soon followed. This desire to be involved was telling of the intimacy in the sibling interactions observed. The interactive nature of this interview allowed for a back-and-forth sibling dialogue on their interactions, letting each interject their respective opinions. The two girls (ASD-S and TD-S) dominated the conversation with the younger brother needing to be directly asked questions in order to share his thoughts. Per this interview, it appeared that there was a more intense sibling dynamic between the sisters. During this interview, the eldest child was also in the vicinity, but chose not to participate directly in the interview although he seemed to be an active listener. The interview with this eldest child was also rather impromptu during the third observation. The parent (mother) interview was held after the three sibling observations were finished. Member checking was especially salient during this interview. There were a few interpretations of mine that were either corrected or given more

contextual background.

Family 3: The Taylors. Parent (mother), TD-S and ASD-S interviews were conducted with this family. All three interviews were done on the same day, after two sibling observations were completed. A certain level of rapport had already been established, especially between the mother, ASD-S, and me. This fostered an interactive and mutually enjoyable interview experience. The first interview was held with the ASD-S, followed by the TD-S, and ending with the mother. This was an unplanned, yet fruitful sequencing of interviews as they allowed for a cumulative effect and offered opportunities of clarification of feedback along the way.

As noted in the discussion of this family's observations, the ASD-S was very engaging and seemed to enjoy interacting with me. This child had a tendency to perseverate on certain topics (i.e., music, music artists, and music videos) and was easily distracted to these tangential topics. Because of this, the interview with this child did not include many of the open-ended questions developed. I needed to practice more flexibility in this interview, allowing for the child to guide the direction of the conversation, with periodic re-directive statements back to topics related to their sibling relationship. Periodic compromises were made with this child in order for him to agree to focus on some of the study-focused questions. Typical of many children with ASD, his responses to questions often didn't follow a linear connection, thought process, or level of clarity. Thus, the follow-up interview and the member checking done with the TD-S and mother helped to provide additional context and correction to interpretations to certain comments made by the ASD sibling.

Family 4: The Andersons. A total of four interviews were done with this family: TD-S interview, ASD-S interview, parent interview (father), and a joint parent interview with both father and mother. Due to the varied summer activities (i.e., sleep away camps), the planned sequencing of the interviews to the observations was not feasible. The first set of interviews (father and TD

sibling) was conducted before any observations took place. This sibling interview was conducted somewhat jointly with his father. His father helped to provide additional information to what was shared by his son and also assisted by scaffolding certain questions to help elicit expounded feedback from the son. The interview with the father was done out of the son's presence. He provided a thorough background of the family's experience with the ASD diagnosis from onset of diagnosis to present. The next interview conducted was with the ASD-S. It occurred impromptu during the second sibling observation. There was a period during the observation where the two siblings disengaged after an argument, and the TD sibling left the room. Based on the nature of the argument and the surrounding circumstances, I took advantage of the opportunity to initiate the interview. Both children were quite articulate in their ability to report on their sibling experiences and express their feelings related to their sibling connection. The joint parent interview was held after two observations had been completed. This parent interview provided additional information and context into the sibling and family dynamics and provided the opportunity to hear the unique perspectives of both parents as they shared their family narrative.

Focus Group Interviews

Focus groups can be a valuable aspect of qualitative studies insofar as they allow for the creation of shared meaning through the sharing of stories (Morgan, 1998). Focus groups participants were included as an additional group of participants in order to obtain additional perspectives from families with a similar family composition (e.g., similar representation of diagnoses/level of functioning of the children with ASD). Moreover, the focus groups allowed me to compare the experiences of a less intimately studied group of families to those of the target families. The focus groups also allowed for an unbiased checking of "accuracy" of my interpretation of the data collected from the target families on similar topics, also known as member checking, a type of verification activity (Creswell & Miller, 2000). I was the moderator of the

groups due to my intimate knowledge of the data and the type of information shared and observed with the target families. This allowed for more productive and efficient triangulation. The focus groups were conducted as part of the final phase of data collection, after most of the information has been obtained from the target families.

The format for the focus groups was comparable to a semi-structured, open-ended interview. Similar to the target family interviews, this format provided initial direction for the conversation but also allowed for flexibility in topics and for new topics to emerge (Morgan, 1998). The group format also supported spontaneous reactions, feedback, and elaborations in the discussion.

Focus group site selection and setting. The selection of the site for the focus groups was not a haphazard decision. The goal was to find a location that offered some level of comfort familiarity, and convenience for the participants. During the phone screenings with the focus group parents, I learned that all of the families had accessed community disability support services, presently or in the past, from social service-like agencies in the area. I was also familiar with these agencies and had a pre-existing professional relationship with key workers at those agencies. Three of these agencies were contacted to request the use of their facilities for the focus group. All three agencies offered the use of their facilities, but the final choice of agency/location was made based primarily on the level of access available to me (including direct building access, materials, games, etc.).

The focus groups were held on a weekend, when agency staff was not typically present. In order to use the facility, the agency requested that an additional person (at my choice) be present in the building for safety. I felt it was important for this additional person to be a clinician with similar professional ethics around confidentiality. Utilizing professional and personal relationships with colleagues, I secured the participation of a clinician who was not only an employee of the

agency but also a clinician who specializes in disabilities. She was informed about the study and had an understanding of the purpose of the focus groups. She did not participate or help moderate any aspects of the groups. Her primary purpose was to be present in the building and help “supervise” the children/parents as they waited in the lobby while focus groups were in session. Since she would have contact, though limited, with the study participants, issues of confidentiality were discussed ahead of time. Based on her profession’s ethical standards, there was a high level of trust in her maintaining the confidentiality of the participants. Furthermore, she did not have any specifics about the demographic information of any of the focus group participants.

Both the FG-P and FG-TD were facilitated by me and held on the same day. The FG-TD was held before the parent group. The parents and any non-participating siblings waited in the lobby/waiting room. The focus groups were held in a conference room where the participants sat around a round table to allow for full visual access to one another. The audio recorder was placed in the center of the table to capture all voices. A more detailed description of the specific interviews/focus groups will follow in the next sections.

Focus group-typically developing siblings. In order to gain an additional perspective on the issue of sibling relationships in F-ASD, a focus group with typically developing siblings of children with ASD was held. Although efforts were made to have a larger group, there were a final number of three (3) participants. This small number of participants allowed for a more intimate setting, greater ease of discussion, and appeared to help with the bonding between the children. The meeting was held within an hour’s time.

The purpose of focus groups is to collect information through group interaction. A common perspective about focus groups is that there is a wide range of methods for conducting the group interviews (Morgan, 2001). Due to the age of the children and the nature of the topic, this group did

not follow the traditional format for focus groups. This particular focus group was a combination of an interview and activity-focused experience. The activities presented were those that encouraged participants' discussion about their sibling interactions and relationships. Activities were planned ahead of time (see Appendix G), and two were done with the group. The decision about the activities was based on the level of comfort and interaction observed between the participants.

At the start of the group, I introduced myself and checked for their level of understanding about their participation in the group. All demonstrated sufficient understanding of the study and their role. I asked the group for their permission to use the audio recorder and allowed them to practice recording and playing back their voices. The group gave their verbal permission for the use of the recorder. More of the interview format was utilized during the first half of the group. An introductory icebreaker activity was facilitated first to allow the children to introduce themselves and share about their siblings with ASD. As the children shared, I helped point out the commonalities between them, whether related to their siblings or themselves in general. After this icebreaker activity, it appeared that a sufficient amount of comfort and rapport had been established to begin with the semi-structured interview questions.

During a natural break in the interviewing, I introduced two activities with the children in order to engage them in a different manner with the hopes that it might elicit a different level of insight and information. The activity was designed to elicit children's perspectives about their family/family interactions based on both 1) from their personal experience, and 2) their perceptions of how others' view them through the eyes of others. Children were given a piece of paper with the outline of a house drawn on both the front and back of the paper. I then explained that the front of the paper represented their family based on what the world thinks their family is like (whether accurate or not). I then told them that the backside of the paper represented what their family is

really like (on the inside). I further explained that how their family truly is may not be the same as how they think others believe their family is. The group was then given the instruction to write or draw their answers on the appropriate side of the paper. In order to make sure the children understood the instructions, I provided an example and showed them one of my own made up answers. After they were done drawing/writing, the children took turns sharing their pictures. Additional questions were asked as each child presented his drawing and this fostered an openness to share in more depth about their sibling and family relationships. The second activity involved having each child think of different animals to represent each member of his family. I then facilitated discussion in which the children explained their choice of animals. The children selected animals that shared traits of their family member (i.e., cheetah because they're fast; Tasmanian devil because she's hyper and all over the place, etc.). Interwoven in both this and the former activity, I utilized additional open-ended questions as they spoke to elicit more information about their sibling and family relationships. Through the sharing during each of these activities, additional insights were given by the children, elucidated by the questions asked to one another by the children. The sharing of one child often triggered a sense of validation and common understanding; promoting additional sharing from the others.

Focus group-parents. The parents of this focus group were the parents of the children in the sibling group. The FG-P was held immediately following the sibling group. The group was comprised of 4 parents (two were husband and wife). This group was also held for an hour. I had several instances of informal communication with the FG-P participants (related to scheduling and other administrative matters) prior to the actual meeting. The prior communications presumably added to the comfort level felt between these participants and me. Likewise, the parents spent an hour in the same lobby/waiting room while their children were meeting with me. Upon entering

into their focus group, they commented that they had been talking while waiting. This pre-group familiarity helped to quickly establish rapport between the parents during the focus group.

This adult/parent focus group followed more of a discussion format for which I moderated the dialogue, utilizing a semi-structured, open-ended question approach. With the goal of fostering a relaxed atmosphere, I purposely did not follow a particular structure for the group (e.g., require the parents to answer in an orderly fashion, no interrupting, etc.). Rather, I presented questions and allowed “the floor to be open” for response. This technique allowed the parents to respond to the question based on their interpretation and helped to elicit dialogue between the parents. The questions presented were related to the parents’ perspectives about their children’s sibling relationship and interactions, their children’s knowledge about ASD, and overall family interactions/relationships (see Appendix G). A palpable feeling of connection between the parents was experienced during the focus group. As parents shared their family narratives, the level of listening and group validation provided evidence that a deeper processing of their personal and unique family situations was occurring and similarities and differences were illuminated. I also used this focus group as an opportunity to share insights gathered from target families and inquired about how these did or did not map on to their personal experiences.

There was a desire to have a third focus group with children/siblings with ASD. However, challenges with group formation (i.e., suitability for participation in an interactive, communications-based group) forced this to be eliminated.

These multi-faceted data collection methods involved multiple layers of perspectives and understanding. With that, in an attempt to show how these procedures and outcomes were situated within the research questions, an integrated data analysis was performed.

Methods of Data Analysis

The analysis of qualitative inquiry is multifaceted and is the phase of the research process where the investigator attempts to organize and interpret the observed experiences. Analysis is an ongoing and iterative process, done throughout all phases of data collection, and starts as soon as the first items of data are collected (i.e., observation, interview, or survey) (Lincoln & Guba, 1985). In this research, analysis began with an inductive approach to the information, guided by the literature, which continued throughout the entire data collection period. In keeping with standard analytic procedures within qualitative research (Miles & Huberman, 1994), a “bottom-up” approach to the analysis was utilized, following a series of analytic phases involving transcription of the data, coding, identification of themes and patterns, and interpretation phases of data collection. I will provide a description of each phase of the data analysis followed by a detailed review of frequency counts and co-occurring categories.

Computer Software and Analysis

Qualitative analytic software helped provide an organizational and structural frame for the analysis. I selected Atlas.ti (Friese, 2012) based on the type of information gathered, as well as its reputation as a reliable and sound qualitative software package (see Lewins & Silver, 2007 and Weitzman & Miles, 1995 for a description of various software programs). Atlas.ti has the capacity to assist with the transcription of various types of data (i.e., audio/visual data, PDF files, etc.) and aids in the entry and organization of field notes, memoing⁸, retrieval and coding of data, as well as graphic mapping and other visual displays of the data. Atlas.ti was used to analyze all forms of data used in this study starting with the questionnaires and progressing to the observations and interviews.

⁸ Memoing is defined as the process of recording one’s ideas and thoughts as they arise during the data collection and analysis phases. Memos were often done as “marginal notes” in the field notes and during data analysis in Atlas.ti.

General Organization of the Data

Password protected files were created for each participant group (professional participants, target family participants, focus group participants) and individual participant unit (i.e., Target Family 1, Target Family 2, etc.). Pseudonyms were used for all participants. As each portion of data was collected, it was immediately transcribed and/or uploaded into Atlas Ti. Within Atlas Ti, the data/"primary documents" (observations, interviews, questionnaires) were identified by its source (specific family, type of participant) and data collection method (observations, questionnaires, interviews) to organize the analysis and assist in comparisons between and across document type and participant type -- for example, examination of observations against interviews (between and within groups). This general organization of the data provided the structural foundation for analysis.

Phase One: Transcription

The first step in the data analysis was the transcription of the data. The process of transcription of observations, field notes, and audio data from interviews was done throughout the entire data collection period. Ongoing transcription is necessary to allow for the continual analysis that occurs in qualitative research. Cosaro (1985) notes that cataloging and transcription of the data is essential to valid linking of information (such as background, setting, and participant information) to the audio/visual data, which he coins as "framing the raw data" (p. 41). Atlas.ti aided in the transcription of the data and allowed for these to be reviewed and additional memoing performed and compared to the field notes taken at the time of the recorded observation.

In most cases, transcription and/or data entry were completed within three days of the event. Similar to decisions about coding (discussed below), judgments about what and how to transcribe

were made. I conducted all parts of the process from data collection through transcription, coding, and analysis. In contrast to some types of quantitative methods, this close connection to all phases of the research is viewed as essential; I have intimate knowledge about the information as it is observed and heard from the participants. This was particularly relevant with the transcribing of the audio recorded interviews/focus groups. During the transcription of the interviews, there were several instances where prior knowledge of the context of the interview, setting, and other circumstances was especially helpful in deciphering the audiotapes during mumbled or very poor sound quality. Without this contextual knowledge, it would have been very difficult, in many cases, to accurately transcribe the information, which might have led to compromised raw data and subsequent analysis. This was equally relevant with the transcription of the written field notes. A self-created “short hand” was used during the note-taking of observations. This was a short-hand that might have been misunderstood by others, and therefore, it was necessary for the same person to transcribe the information, understanding the short-hand per observational context/episode. In considering the integrity of all of the data received, it was decided that transcription of written (i.e., questionnaire) or oral (i.e., interview) data by a participant would be transcribed in its true form, exactly as originally given regardless of spelling or other grammatical errors.

Phase Two: Coding and Categorization

Coding. As part of the early analytic process, coding was used as a way of organizing the raw data. Miles and Huberman (1994) define codes as labels given to descriptive information (e.g., words, phrases, sentences), with the purpose of establishing meaning to segments of the data. This is in contrast to quantitative analysis where coding refers to applying a numerical value to the data. The goal of coding in qualitative research is to retrieve data categorized under the same code (Coffey & Atkinson, 1996), which may lead to new questions and interpretations about the data.

Coding took place both during and after the data collection process (Miles & Huberman, 1994).

Prior to examination and coding of the raw data, an *a priori* list of codes was developed based on my theoretical framework, the research literature and my professional experience on the topic.

These *a priori* codes were fluid and were modified and expanded as I moved through the analytic phase (Miles & Huberman, 1994). Emerson, Fretz, and Shaw (1995) suggest a guiding list of questions to ponder while coding the data. These questions were critical for my refinement of the codes and initial identification of patterns in the data: 1) What are people doing and/or trying to accomplish? 2) How are they doing this? What specific strategies do they use? 3) How do the participants/people talk about, describe, and understand what is going on? 4) What assumptions are they making? 5) What do I see going on here? What did I learn from these notes? and 6) Why did I include them?

There is debate between qualitative researchers about how much of the actual data should be coded—every recorded piece of fieldwork versus select portions of the data. My approach was somewhat mixed, but more consistent with the former (Strauss, 1987; Wolcott, 1999), where every piece of data was coded and analyzed. Because of the fast-paced aspect of family life, I wanted to examine even the minutiae of interactions that might offer salient insight. The coding process involved reviewing each transcript line by line, looking for and marking key or recurrent words, phrases, and patterns in the participants' narratives. There were times when “sectional” or “episodic” coding was performed. In such instances, there were sections of the transcript (i.e., a paragraph or an episode of discussion) that represented a particular concept. That entire section (vs. each repeated comment of the same topic) was highlighted and assigned a code(s). The cyclical act of coding not only involved linking of concepts to the raw data, but also linking of these concepts together, thus formulating “ideas” about the data. One way this was accomplished was through *co-*

occurring codes. Co-occurrence of codes happens when the same segment of data is coded with more than one code/has more than one code attached to them (Frieze, 2012).

The first segment of data to be analyzed through coding included the professional questionnaires. As the coding process began, it became evident that the original list of *a priori* codes was not valuable for the data actually collected. I did not want to bias the data by forcing or applying the *a priori* codes, but rather have the codes emerge from the actual data itself; otherwise known as *open coding*. With open coding, the researcher generates codes *from* the data as opposed to applying them *to* the data. Eventually, the majority of the original *a priori* codes were deleted and a more descriptive, new set of 110 codes were created (see Appendix H). This was a critical exercise insofar as it helped me to think more critically about the data and the information that was emerging. The codes developed were then used to reduce the information into categories (Bogdan & Biklen, 1992, Emerson, Fretz, & Shaw, 1997).

Categorization. Coding was the first step leading to categorizing of the data. Through the codes, the raw data were arranged in a systematic order in order to later group or organize the data into categories (called *families* in Atlas.ti). These categories were formed based on coded data that shared similar characteristics. These categories were developed both through an intuitive and deductive process (Lincoln & Guba, 1985). Categorization occurred as the initial, *a priori* codes, were refined into a more specific and detailed codes. Categorizing links similar concepts and also identifies various layers or dimensions of concept. Bogdan and Biklen (1992) suggest the use of topical codes such as setting and context, perspective, process, activity, and relationship. Twenty (20) categories were initially developed from the data (Appendix H). Examples of categories and their related codes are: Level of Involvement (codes: engaged, disengaged, etc.); Sibling Adjustment/Coping (codes: embarrassment, acceptance, frustration, pride, etc.).

Upon closer examination of the data, two categories failed to demonstrate consistent relevance: **ASD communication ability** and **Severity of ASD**. The target family children with ASD were of comparable communication ability and had similar diagnoses (and relative functioning levels). Thus, differences on these levels were not strong. The ASD siblings represented by the focus group families were also of similar communication abilities and diagnoses/functioning levels, with the exception of two children. However, their communication and functioning differences were not salient issues discussed/presented in terms of the sibling relationships. While they were not officially deleted, they will not be discussed.

Assessments of validity. The coding process is the foundation for analysis. Subsequent categorization and theme development are outcomes of the coding cycle. For this reason, reflective and “checking” activities were done to assess the soundness of the interpretations of the data being made. I engaged in various *peer debriefing* activities to evaluate the accuracy, relevance, and applicability of the codes and categories identified. As the sole coder, I had regular consultation with my faculty advisor about the coding and analysis. Likewise, emerging codes and categories were shared with both student and professional colleagues (familiar with ASD) for internal validity checking at various steps in the analytic process. These activities offered opportunities for discussion about uncertainties during analysis and helped to find new connections within the data. For example, I led my lab team (a group of doctoral students who meet on a regular basis with two faculty mentors) in a blind process of grouping various words (codes) and then labeling each group (categories). While they were aware of the topic of this research, they were not involved in the data collection. The lab team’s breakdown was strikingly similar to how I had categorized the data. I led a group of professional colleagues through a similar task which also yielded similar results. This activity helped to confirm certain analyses and resulted in the deletion or merging of codes and

re-categorizing as needed. This step of coding and categorization yielded a total of one hundred and ten (110) codes within twenty (20) categories.

Phase Three: Interpretation and Identification of Patterns and Themes

The goal of the interpretive phase is to clarify and bring meaning to the participants' experience with the phenomena (Denzin, 2002). The identification of themes may involve additional coding phases of axial and selective coding (LaRossa, 2005; Wolcott, 1994). *Axial coding* encompasses the exploration of the relationships between and among variables, with particular attention given to coding data for relevance to the categories and subcategories identified across field notes, experiences, conditions, and subjects. *Selective coding* brings together categories to the identification of a core/central category. The assumption is that all of the major categories are related to this central category. LaRossa (2005, p. 850) describes selective coding, as "the main story underlying analysis."

In these next phases of coding, I conducted analyses around individual categories exploring the relationship between and among the variables (LaRossa, 2005; Wolcott, 1994). To search for emerging patterns in the similarities and differences across interviews, I developed visual displays of the data during coding (Miles & Huberman, 1994).

During the phase of axial coding, a deeper examination of the relationship between the categories was done. Coding for patterns was a large part of the process. It was found that there were three main types of categories: "relational" categories, "fact/descriptor" categories, and "supports/resources" categories (see Figure 2). Much of the substantive data from which the themes emerged were from the relational categories. The relational-oriented data guided the formation of themes and overarching notions about sibling relationships in F-ASD (Creswell, 2003). Further examination into the associations between the category types uncovered another level of relation

where the fact/descriptor and supports/resources categories helped to inform the relational categories (and theme development).

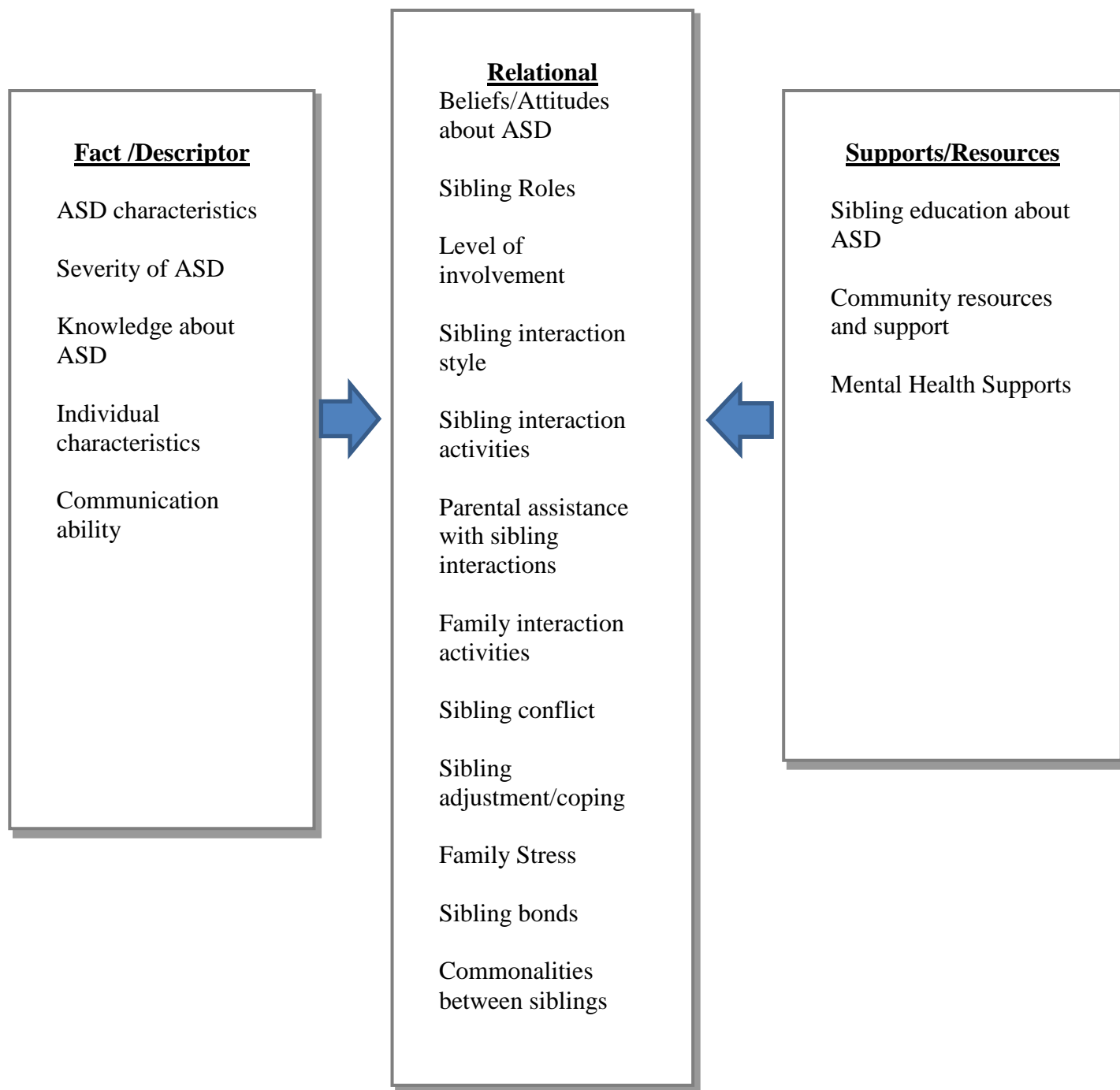


Figure 2. Types of category domains

Further content analysis was performed where additional hierarchical relationships between the codes and categories were found. The relational categories further clustered into three groupings: sibling behavior/interaction, sibling status/commitment, and parental/family influence (see Figure 3).

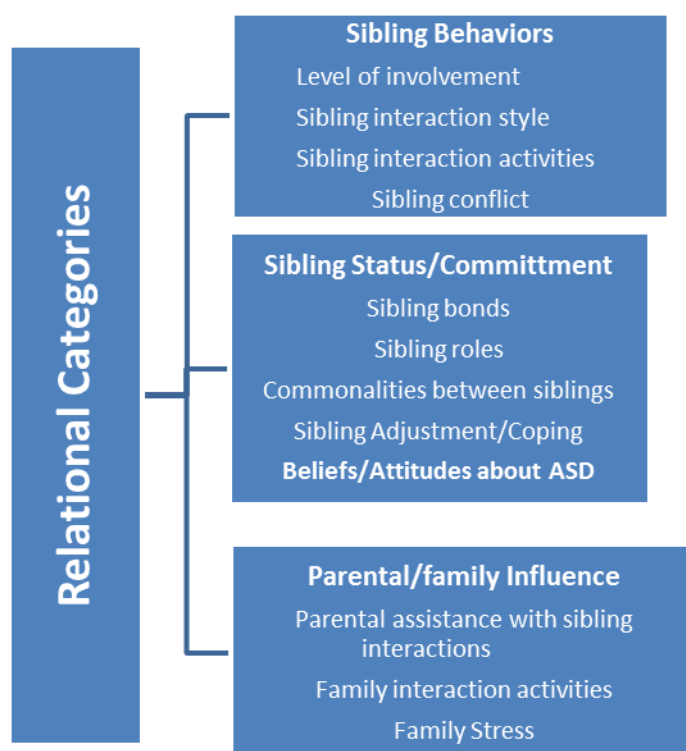


Figure 3. Groupings of relational categories

Frequencies and co-occurring codes. Frequency counts were calculated for all of the 20 categories and their corresponding codes, across participant groups and data collection activities to yield the most frequently occurring categories and codes. Comparisons were also made from these frequencies across participant groups. Frequencies were calculated in order to gain a better understanding of the most salient issues expressed and/or observed by the participant families. Calculating frequencies allowed me to identify the most frequently noted issues (per the categories) and the related details of those issues (per the codes within the categories) in order to better describe the complexities of the sibling relationships and interactions.

Analysis of co-occurring categories was also done to explore relationships between categories/concepts. This analysis was produced as a report via Atlas.ti, looking at the frequency of the number of times/event of codes/categories overlapped/co-occurred within the raw data (i.e., quotations). These overlaps suggest relations between concepts that eventually lead to the formulation of patterns and themes. Across participant groups and data collection methods, there were a total of 12 categories that co-occurred. Several other categories also demonstrated some co-occurrence, albeit at a less frequent rate(see Appendix I).

Narrative Analysis. Aspects of narrative analysis were employed as part of the overall data analysis conducted. Narrative analysis helps to focus on the way in which participants can communicate and make meaning of their experiences. The personal narratives (via family interviews and focus groups) of the participants were used to better understand the individual sibling experiences of these families. The rich and descriptive narratives analyzed served as interpretive devices; allowing the family members to describe their specific circumstances. Consistent with narrative inquiry, of particular interest to this study was how the stories reflected the families' values, interpersonal interactions within the family, and how the overall content revealed the families' lives and how they situate themselves in the account. Narrative analysis also allows the researcher to examine relationships (agreement and disagreement) between the stories shared by the individuals within the same family (Daly, 2007). Additionally, narrative analysis allows one to use various theoretical frameworks as the lens through which the story may be examined.

Through the narrative analysis, certain contextual patterns of experience emerged across families. Gender, age, and role differences were also discussed. The use of a narrative inquiry within the case stories of the families offered multiple perspectives in understanding the sibling

relationships (and related family influences) in these families of children with ASD. As part of the analysis, I was especially interested in the repeated patterns/themes shared within each story and the significance of those patterns. Strauss and Corbin (1998) propose multiple readings of transcriptions as the essential activity from which the investigator then provides labels to the patterns or recurring concepts.

Themes. Themes were developed based on patterns found in the data. Specific patterns that were found within individual families or participant groups were compared and refined through further analysis until central themes across participants were identified. As suggested by Strauss and Corbin (1998), after the themes were synthesized into a core set of categories, narrative explanations for these themes within participants were developed. As these themes were identified, narrative explanations of the phenomenon were given, leading to the findings. These findings will be discussed in Chapter Four.

Phase Four: Verification of the Data

Ensuring data quality and rigor is an important component of qualitative research (Krefting, 1999). This was especially important given this study had a small sample size, though this is not unusual for qualitative research of this type. Qualitative research has inherent limitations that can be reduced through methods such as triangulation, member checking, peer debriefing, and establishing an audit trail (Creswell, 1994; Daly, 2007; Krefting, 1999; Lincoln & Guba, 1985). Just like the data analysis, verification activities should be an ongoing, continuous aspect of that process.

Triangulation is the merging of multiple perspectives or “cross checking,” for confirmation that all aspects of the phenomenon have been explored. I employed three types of triangulation: triangulation of data sources, triangulation of data methods, and theoretical triangulation. With regard to data sources, I was able to recruit a somewhat diverse sample of participants, representing

variation in: 1) family backgrounds, 2) family constellations, and 3) the timing of the diagnosis of ASD and the level of understanding of the diagnosis of ASD. Multiple perspectives were obtained through the use of the target families and the subgroup of focus group families. As Daly (2007) notes, this decision helps to maximize the variability of experience between participants.

Furthermore, the multiple methods of data collection (interviews, focus groups, and participant observations) allow for a broader examination and understanding of the research questions.

Theoretical triangulation was also be used to address the issue of data credibility. As described by Daly (2007), this involves “bringing to the research a number of disciplinary perspectives or theoretical approaches” (p. 257). My application of two theoretical perspectives, the Transactional and Circumplex models, provided a greater depth to the interpretation of the data.

Member checking is a technique that was employed to ensure that my interpretations accurately reflected the experiences of the participants (Lincoln & Guba, 1985). Member checking is especially important because only the sources of the data, the participants telling their personal stories, can verify the authenticity and accuracy of the data (their narratives) and the assigned interpretation. Member checking was most targeted during the various parent interviews (the target family parent interviews and the parent focus group). Interpretations of certain aspects of the sibling relationship were checked also with the child participants. Having the interviews occur after observations had been completed (target families) and near the end of the data collection phase allowed me to have data to share. With the target families, I reviewed certain interactions observed between the siblings and asked for impressions and interpretations. With the focus group participants, I shared some of the emerging patterns of interaction observed with the target families and inquired about the any similarities to their own experiences. Krefting (1999) notes that member checking can also be done by sharing information obtained from one source (e.g., target parent

interview) with another source (e.g., focus group) to check for clarification and accuracy based on the phenomenon. While the focus group members could not speak to the accuracy of another participant's experience, they were able to provide insight into the parallel or dissimilarity of experience. This feedback from families was compared against my own interpretations (Cosaro, 1985). Member checking allows for the participants to provide additional contextual information that might help explain some of the observations seen. This step helps to reduce inaccurate interpretation resulting from gaps in information.

Peer debriefing was another major verification procedure used. It is essentially sharing with neutral or uninvolved peers the data/themes identified for the purpose of obtaining other possible connections, perspectives and interpretations. Peer debriefing also allows the researcher to be made aware of her positioning and biases toward data and analysis (Krefting, 1999, Maxwell, 2002). Peer debriefing was conducted one four occasions during the data analysis with three different groups. Towards the beginning and midpoint of the data collection, the same group of professional colleagues (social workers and counselors specializing in ASD) was presented with the emerging codes and categories, along with the coding and categorization process, for their feedback on my decision-making. To reduce any desire to respond favorably to me, the peer debriefing exercises were done as "blind" tasks where I did not initially provide my personal decisions and conclusions until the entire activity was completed and their feedback had already been provided. This same activity was done with fellow students and university mentors. The group discussions that ensued were pivotal to modifying and refining the coding and categorization process. There was another peer debriefing activity performed towards the end of the data analysis when patterns and themes were emerging. I had the opportunity to orally present the study, the procedures, and the emerging findings with a group of professionals comprised of pediatricians, psychologist,

psychiatrists, therapists, special educators, and other related professionals. I solicited feedback from this professional group around their thoughts of the integrity of the procedures and interpretations of the data. The comments obtained from these discussions were integrated into the research process as appropriate.

Finally, an *audit trail* was developed through my use of documentation of decisions and strategies used throughout the data collection and analyses process. A separate notebook was kept in which each step of the recruitment, data collection, and data analysis was entered. This helped to track each process for later review if/when refinements were made. This audit trail enhanced the dependability of the study and may assist in any further studies attempting to replicate or gather similar data. Moreover, this audit trail included personal thoughts and reflections that emerged over the course of the process, including insights to any personal biases or researcher-participant interaction struggles I encountered.

Chapter 4: Findings

In this chapter, using the research questions as a framework, I discuss the six themes (overarching and five subthemes) that emerged from the data analysis.

Themes

Analysis of the observations, interviews, and questionnaires yielded one central theme and five contextual or descriptive subthemes that described sibling relationships within the family context. Looking at the family as a unit, the overarching theme was: *Family life as usual: Family life continues but with adaptations*. As a subsystem of the larger family unit, sibling relationships appear to be a function of overall family order and cohesion. The five descriptive subthemes that developed help to describe the family order or processes, specific to sibling relationships in the target families (see Table 6). Understanding sibling relationships is complex. The theme and subthemes provided a means to organize the data and see common threads of interpretation that connected the research questions. Each will be discussed within the context of the applicable research question.

Table 6

Central Theme and Subthemes

<u>Overarching Theme:</u>	<u><i>Family life as usual: Family life continues but with adaptations</i></u>
<u>Descriptive Subthemes:</u>	<ul style="list-style-type: none"> • <u>Subtheme 1:</u> What's the best thing about having a sibling? Friendship: <i>ASD sibling relationships are similar to typical siblings but with unique qualities</i> • <u>Subtheme 2:</u> "Figure it out. You need to compromise!": <i>Parental involvement serves as an interpretive lens</i> • <u>Subtheme 3:</u> People with autism are no different than you, they just need a little help.: <i>Perspectives about ASD matter</i> • <u>Subtheme 4:</u> I'm not a fan of ASD: <i>ASD brings complexity to the sibling relationship</i> • <u>Subtheme 5:</u> It takes a village: <i>Community resources and supports provide acceptance and education</i>

Family life as usual: Family life continues but with adaptations

The sibling subsystem is part of the larger family unit. Assuming that bi-directional influences occur at all levels, how the larger unit addresses and interprets ASD would influence how the other family subsystems respond. The overarching theme *Family life as usual* touches on this idea. All participant families (target and focus group) acknowledged that ASD added a unique element to their family; and they found a way to embrace and integrate ASD into their family life. While accommodations were needed to support the family units' overall well-being, ASD did not alter the core of the families' structure and organization; indicating that their life continued as usual in most respects.⁹ Victoria (FG-P) said it well:

...our concentration was making Emma a part of everything we do. So, that was our emphasis from the start... We just said, "Okay, we're gonna continue as we would do if she didn't have autism and she's gonna come along for the ride. And it's been quite the ride".

The way in which the families engaged in their daily lives also demonstrated this value. Diane, a mother of triplets with ASD, shared how the birth of her sons created an unexpected change to the family routine. During a focus group interview, Diane spoke of how her eldest son, Charlie (TD-S), had a difficult period of transition when her triplets were born. She poignantly described:

And then all the sudden, pow, he's got this gestational phenomena (gave birth to triplets). And it really...you look at our family. There's six of us. Half of us are neuro-typical and the other half of us have ASD. So, it changes the balance quite a bit. But the norm around our house is a little different that the norm in most people's houses just because of the sheer numbers

Diane also noted how once the shock of the change was processed, Charlie and the rest of the

⁹ Frequency information referenced early in Chapter 4 (high frequency categories and related codes) will be inserted periodically to demonstrate connection between the frequencies and the theme development.

family were able to figure out their patterns and re-establish equilibrium.

Families also expressed a level of acceptance of the ASD and have integrated the disorder and its effects into their daily lives by virtue of the fact that the diagnosis is pervasive and long-term. Richard (TF-P), stated, "...it's never gonna be fixed. That's all it is. You learn to manage and deal with it. ... it's always there." How the ASD gets integrated into family life was often accomplished by making changes in how they approach daily routines. Kimberly's (ASD child) mother, Linda reported, "...lots of our activities are what Kimberly wants to do. ... She dominates a lot of the decision making. ... In terms of decision making things, sometimes it's just easier not to fight with her." Such perspective and approach was commonly shared by the families. This level of accommodation occurred even for seemingly the simplest of decisions, such as modifying what kind of movies the family would see (i.e., regular vs. 3-D movie) based on what the child with ASD could tolerate and/or to reduce discord during family outings.

RQ1: What is the nature of sibling interactions in families of young children with ASD?

The themes that emerged related to this research question suggest that, similar to any sibling relationship, the nature of the ASD-TD sibling relationships involved aspects related to their level and type of involvement, their sibling bonds, and their conflict. Observations of sibling interactions and the target family/focus group interviews were the primary source by which this question was addressed.

Theme 1: What's the best thing about having a sibling? Friendship: *ASD sibling relationships are similar to typical siblings but with unique qualities.* Across families, the siblings (typical and ASD alike) expressed and/or demonstrated a wish to engage with their brother or sister.

This desire for companionship remained present despite any challenges in their sibling relationship.

Zachary's (TD-S) answer to my simple question serves as an example¹⁰:

Jamell (J): ...So, let's see...what is the best thing about being a brother?

Zachary(Z): Friendship.

Many of the typically developing siblings shared stories of how they yearned for a relationship of mutual enjoyment, and would go to great lengths for some acknowledgement from their sibling.

Greg shared his experience which was representative of many other siblings, "Yea, 'cause when I was four I wanted to play with him so badly. He would punch me and he would get in time out and I would sit right next to his door until he got out." ASD siblings also articulated a desire for connection with their siblings. Kevin, the brother of Greg, spoke of his want for a playmate as he answered a question about his perspectives on his sibling relationship, "Well, sometimes at least you have someone to play with all the time. And um, you have someone who actually knows ...who actually can do stuff with you without being so busy." Hence, the longing for friendship through one's sibling(s) was a mutual desire, although not always fully realized.

Mutuality in involvement. Issues around involvement were a universal challenge for all of the siblings, especially witnessed with the target families. Many of the parents noted that their children spent a great deal of time doing individual activities and were often not even in the same room with one another much of the time. When in the same vicinity, parents often said that their children would be watching TV together but not interacting. When coming to the homes to conduct the observations, I would often be greeted with statements similar to the one from Barbara, "I don't know how much interaction you'll see today." Many parents noted that the lack of involvement and engagement between siblings seemed to be due to lack of common interests. The development of

¹⁰ In conversations, the speaker will be noted by first initial throughout the dialogue after the first introduction of the name of the speaker. For example, J: represents Jamell.

mutual interests or lack thereof emerged at different times and different contexts. Reciprocity was another level of this mutuality. On the one hand, the deficit in reciprocity for the ASD-S is an example of how it was difficult for some siblings to establish mutuality in their relationships. Trials to reciprocity, including the lack of mutual interests, were a common challenge that permeated the sibling relationships. This lack of unifying interests limited the desire for interactions and contributed to some of the conflict between siblings. This will be discussed further in later sections.

On the other hand, there were moments of reciprocity and shared turn-taking. Despite the lack of shared interests and the reported lack of interaction, when they were jointly engaged, siblings demonstrated mutual enjoyment in their interactions. Observations of sibling play in three of the target families revealed not only reciprocity, but also an element of shared turn-taking in their play. This was somewhat unexpected given the nature of ASD and the lack of mutuality that is often cited as a characteristic of the disorder. A glimpse of this type of mutuality and reciprocity was seen between Zachary (TD-S) and Blake (ASD-S) during an extended episode of joint attention and engagement while playing with transforming sponges that expand in water:

Blake (B)-Z: (looking at the few capsules in the water) Yep, they're evolving sponges

Zachary attempts to prompt Blake to put his capsules into the bowl, but Blake is moving slowly as he is still distracted by the pictures.

Z-B: Here, I'll help you.

Zachary picks up all of Blake's capsules and puts them into the water. The boys are intensely gazing at the bowl watching the capsules as they slowly melt and open up.

B-Z: You have an evolving sponge.

.....

B-Z: No, it's an anteater. Zachary, do you hope one gets wings?

Z-B: Well, I hope three get sharp teeth. I hope 20 of

them get sharp teeth. The cheetah and the lion.

For Zachary and Blake, these fleeting bouts of reciprocity and mutual enjoyment were often seen during imaginary play when the theme of play involved aspects of the interests of both children (i.e., dinosaurs or related creatures (Blake) and imaginary planets (Zachary)).

The shared turn-taking in play was observed most with the Smith twins, but also with the Anderson children. For these brothers, the turn-taking also had an element of control or leadership when in play. Greg (TD-S) and Kevin's leadership in play was seen most driven by their skill set or abilities during the specific game. For example, when playing an athletic game (i.e., baseball or basketball), Greg was often observed dominating the game. Greg, being the more skilled athlete, would often become irritated by Kevin's playing and would try to direct his playing moves. During games where intellect and strategy skills were more needed (i.e., video game of military strategy) Kevin's strengths emerged and allowed him to show his leadership:

The boys continue to play the game. The boys go back and forth telling each other how to make certain moves to earn points. Periodically they each make sarcastic "digs" to each other on their playing.

Kevin (K)- This is the easiest
Greg (G):
G-K: No it's not. You call this
easy?

The boys continue to play the game.

K-G: Was this easy?

G-K: Yes.

K-G: What did I say?

(referring to his early comment about this part of the game being easy to complete).

Greg and Kevin are but one example of how the mutuality shared between siblings is informed not only by their level of commonalities of interests, but also bound by the abilities of

both children. One of the professionals (P1) noted, “Siblings [TD-S] report that they cannot play with them [ASD siblings] as much when they get a certain age because interests change and/or the sibling with the disability can’t physically do it.”

Parents also spoke of how the abilities of one child often helped to support the shortcomings of the other sibling. Victoria (FG-P), spoke of the awareness that her daughter, Emma (ASD-S), had comparing her social shortcomings to those of her brother. Victoria (FG) noted that her son, Paul, has been a natural social model for her. During an observation of the Taylors¹¹ (TF) family, I witnessed how Christopher’s (ASD-S) strengths, which included social outgoingness drew out some sociability in his brother, Daniel, whom prior to this incident had engaged very little with me:

Christopher (C)-J:	Can I tell you a joke?	
J-C:	Sure!	
C-J:	Why did the chicken cross the road?	
J-C:	Why?	
C-J:	To get to the other side.	<i>(Laughing)</i>
		<i>I laugh with Christopher. Daniel stands up from the couch and faces Christopher and me.</i>
Daniel (D)-C and J:	No, no. Why did the chicken cross the road? Because the egg rolled.	<i>Even though Daniel is looking at Christopher as he says the joke, I also laugh with them.</i>
J-D:	Did you just make that up?	
D-J:	No, a long time ago.	
C-J:	Why did the clown fall off the unicycle? Because it got hurt.	<i>Christopher starts laughing. I giggle with him.</i>

ASD’s influence on the typical sibling relationship. The influence of ASD on sibling interactions that would otherwise be considered “typical” was seen in multiple facets of the sibling relations. In describing their children’s sibling relationship and interactions, many parents highlighted the similarities to typically developing sibling pairs, but noted that the ASD influenced

¹¹ Target families will be referenced by either first name or family surname. Focus group families will be referenced only by first name. The professional participants will not be discussed by name.

the relationship. The way in which the ASD “came into play” was seen during an exchange between the Johnson children. The social impairments of ASD surfaced during a joint sibling interview with Kimberly (ASD-S), Jennifer and Louis (younger TD-S). Here, Kimberly is engaging in the “typical” ribbing or “light teasing” that often occurs between siblings. However, her impaired social judgment led to a moment of embarrassment for her siblings:

- Jamell (Ja): Okay, so you told me a lot about Jennifer, about yourself...what about your brothers?
- Kimberly (K): Okay, Thomas...well um, Thomas...well, they're both mouth breathers. *Thomas is across the room listening.*
- Jennifer (Je): Hey! That's not nice. You always say mean stuff.
- K: That's actually uh....that's actually a comment. Mouth breathers, you know how they (she imitates mouth breathing). They're both mouth breathers...
- Je: You're a mouth breather.
- K: And Louis and my little brother ...um...sometimes drools on the bed. (everyone chuckles)
- Je: You're being so mean.

Although one could argue that siblings, in general, may have moments of insensitivity (perhaps intentionally) towards their siblings, in this example Kimberly missed an “unspoken” social rule. She engaged in prolonged teasing to a point where it subtly shifted to the mention of “secrets.” The type of information Kimberly shared might be considered slightly inappropriate for her audience (an unfamiliar adult researcher).

The social deficits of ASD also emerged as a component to sibling strife during one observation of Kevin (ASD-S) and his brother, Greg. Typical to the ASD-TD sibling pairs, the lack of ability in reading social-cues was observed during a game of Monopoly. Kevin (ASD-S) was dramatically beating his brother and a friend. Greg had been giving hints to his growing frustration with the game (due to his perpetual loss of money), yet Kevin continued bragging about his amount of money while highlighting the “bad luck” Kevin and the friend were having. Kevin's comments

only added “fuel to the fire” to an already stressful situation on the verge of a meltdown:

G-K: Sucker. Take your rotten money. *(Throws the money at Kevin)*
 K-G: Greg, what’s wrong?
 J.J.-K: What do you think is wrong?

Kevin seemed genuinely surprised by his brother’s reaction to losing. This interaction ended with Greg disturbing all of the game pieces and taking all of the money and throwing it up in the air. Shortly thereafter, the game ended with Greg and his friend disbanding leaving Kevin confused about the outcome. A similar example of lack of social understanding was seen between Blake (ASD-S) and Zachary (TD-S). During a moment where Blake was initiating engagement with his brother, he failed to notice the growing irritation in Zachary related to the play he was forcing on his brother:

		<i>Blake continues to drag his “Sheety” (a favorite blanket) around with him to the basement and continues to pretend to be a ghost/monster and chases Zachary. Zachary doesn’t seem to be interested in playing the game with Blake.</i>
Z-B:	The more angry I get, the more monster I get.	<i>He also postures as if he has claws coming out of his hands.</i>
B-Z:	Stupid. Stupid.	<i>Blake is chasing Zachary around calling him stupid and making other comments asking Zachary to get pretend angry and act like a monster.</i>
B-Z:	Ah ha, your butt is the stupidest in the world and dopey.	
Z-B:	Blake, now you made my scratch venomous.	<i>Zachary is pretending to be monster and is posturing like he is about to attack Blake. It is not clear if Zachary is finding this to be an enjoyable game. There seems to be an underlying level of frustration from him.</i> <i>Blake continues to chase Zachary and invades his space; still covering himself with his “Sheety.”</i>

Z-B and J: Monsters can stand
 anything but sheets.

As an onlooker, it seemed as though Blake was encouraged by the heightened emotional response expressed by Zachary; not fully realizing he was making him angry and that it was not a mutually enjoyable game. This exchange culminated with Zachary becoming physically aggressive with Blake and their mother needing to separate the two of them. Despite the misreading of cues, this exchange points to Blake's momentary desire for interaction with his brother.

Distractibility and perseveration. The distractibility and perseveration common to ASD also emerged as salient contributors to the level of frustration for many of the TD siblings. This was seen most often with Daniel (TD-S) towards his brother, Christopher; although expressed by all of the typically developing siblings. Christopher tended to perseverate over various topics and would often try to engage others in his circular conversations. During one observation, after several other repetitive questioning bouts, Daniel seemed unable to contain his irritation:

C-J: Jamell, what's your
 favorite TV show?
J-C: "What about your favorite
 show?
C-J: What about Annoying
 Orange?
D: What about (*mocking Christopher*)
Mother (M)-D: Don't do that. That's
 rude."

A similar reaction occurred between the Smith brothers. Blake (ASD child) had been engaging in a long monologue about dinosaurs.

		<i>Blake continues his monologue about dinosaurs. Zachary gets up and walks around the room as if to try to figure out what to play. (overhearing something that Blake said)</i>
Z-B:	What does that mean?	<i>Blake gives a really quick response</i>
B-Z:	It means____	
Z:	It means blah, blah, blah	

The distractibility and “peripheral” active listening style seen with Christopher and Blake contributed, not only to frustration in the TD sibling, but also encouraged intermittent or brief negative encounters between siblings. However, when these unexpected fleeting moments of connection occurred, the input was often relevant and appropriate. For example, during an observation of the Smith twins, Blake and Zachary were each involved in different activities on opposite ends of the room. Despite Zachary’s attempts to engage with Blake, Blake was intensely focused on his activity and gave all outward signs of ignoring Zachary. However, at a random moment, Blake spontaneously interjected his feedback into a conversation held between Zachary and me about Power Rangers (action figures and cartoon characters):

Z-J: My favorite is Jungle
Forest
B-Z: No, it’s Wild Forest.

Z-J and B: That’s right, it’s Wild
Forest. I just like to call it
Jungle Forest.

Zachary continues to tell me a few more facts about Power Rangers. Blake periodically jumps in and adds a few comments or corrects Zachary on certain details.

J-Z and B: So, who are the characters
in Power Rangers Wild
Forest?
Z-J: “White-Tiger; Yellow-
Falcon; Red-Lion; Black-
Wildebeest...
B-Z and J: No, Bison

Z-J and B: That’s right, Bison. Or
Wildebeest.

Similarities to typically developing sibling pairs. Notwithstanding the unique aspects of the sibling interactions seen in the study families, there were also sibling dynamics that mirrored those of typically developing sibling pairs. For example, the minor arguments observed were often

similar to the conflict expected in any household. I recall Mrs. Taylor commenting how her sons were always “going at it” or “being boys.” This type of conflict observed with her sons was often around common issues of sharing the remote control or fighting over preferred seating on the couch, etc. Much of the conflict observed between the Johnson children was typical to what is often seen between many sisters. During a joint sibling interview, Kimberly (ASD-S) and Jennifer engaged in a bout of teasing as they told me a little bit about themselves:

K: Jennifer. And her birthday’s in September...29th.
 Je: I’m supposed to tell it.
 K: And um, she’s kind of mean to me.
 Je: Hey!
 K: Bossy...
 Je: Hey! You’re bossy to me.
 K: And she has a pink room, she likes princesses...
 Je: Hey!
 (the girls are poking at each other)

I learned that these moments of teasing occurred as part of their daily sibling experience and their reactions to the teasing were age appropriate and typical of most children. Kimberly shared her own embarrassment, “Miss Jamell, what you can expect from families is if you do something embarrassing, they’ll tell the whole world.” I also witnessed another moment of the typical “picking” that siblings often do between Kevin (ASD-S) and Greg:

		<i>As Greg walks into the kitchen area (where Kevin is also sitting), he walks by Kevin.</i>
G-K:	Whatcha doing?	
K-G:	Watching a video.	
G-K:	About what?”	<i>Greg walks by Kevin, slightly pushing him as he passes him.</i>
K-G:	None of your beeswax.	
G-K:	Your face.	<i>Mother tells the boys to stop picking at each other.</i>

Conflict. As noted, conflict was just one of the ways in which the ASD-TD sibling pairs were similar to typically developing sibling pairs (Ostrov et al., 2006). The way in which the conflict appeared was typical to any sibling pair: instigating, arguing, and mild physical aggression. However, the underlying *cause* of the conflict may have had an additional layer of complexity. In many cases the conflict observed (or reported) was related to the impact of the ASD on the sibling interactions.

All of the children were aware of and acknowledged the conflict whether or not they were fully aware of or attributed ASD as contributing to or the source of the strife. For example, although Christopher did not go into detail about the conflicts he has with his brother, he was very aware this was an issue for the pair. When asked for his opinions about having and being a brother he replied, “Do not fight.” He commented that this was an instruction often given by their mother due to the frequency of their arguments. Greg (TD-S) showed insight into how his brother’s ASD contributed to their arguments. Although the arguing, in and of itself, seems fairly typical, the reason behind the argument centers largely around the inflexible thinking that many children with ASD experience. Greg shared with me why he and Kevin often don’t like to play together:

Because if we’re on the same team, we’ll probably get into a fight in the dug-out. (Greg quickly recites an example of a play Kevin would have wanted him to make that he didn’t do exactly right. Greg also imitates Kevin swatting the air in anger)... and might try to slap me. Like, that’s the bad thing about Asperger’s. Like, he doesn’t work it out too well.

He went on to describe more of the rigid thinking that contributes to their conflict, “He makes the rules fair for him. He goes like, “only left-handers can play.” And he’s the only left-hander on the field. Or like, “Only left-handers can pitch.” He’s the only left-hander.”

Some of the conflict between the siblings was related to impulsiveness and difficulty with

self-monitoring and regulation common to children with ASD. One episode between Blake (ASD child) and Zachary exemplifies the moments of intense conflict between siblings because of these behaviors. Zachary's reaction below occurred after his brother, unprovoked, violated his personal property:

Z:	(Zachary shrieks).	
B:	Only two Rangers alive! Blake ripped up my cut-outs!	
Z-B:	Only two Rangers alive! Shame on you!	<i>Zachary runs downstairs to his mother telling her what Blake has done.</i>
J-B:		
B-J:	Your brother seems pretty upset. I hate everything but prehistoric stuff. I hate almost everything.	<i>Mother comes upstairs and begins to intervene.</i>
Mother (M)-B:		
B-M:	What happened?	
M-B:	I don't want to tell you.	<i>As Mother is having this conversation with Blake, Blake proceeds to rip up another cut-out of Zachary's.</i>
B-M:	Why do you rip up Zachary's stuff?	

The desire to engage, although facing rejection, was a recurring sentiment shared by and observed in the TD siblings. The rejection by the sibling with ASD was often a reflection of their differing interests, as expressed by Daniel (TD-S), "He just doesn't like to do stuff with me often." The incompatible interests coupled with the rejection often resulted in a clash:

C:	I wanna draw! Can I draw?	<i>(said with irritation). Christopher shouts this out but I wasn't looking over in their direction to see what happened.</i>
C-D:	Can I draw?	<i>I look over and I see that Daniel is standing up with a small Nerf football in his hand. He is facing Christopher and is pretending to throw it at him.</i>

D-C: Catch it and then throw it
back at me.

C-D: But I want to draw. Can I
draw?

D-C: Just throw it in my hand.

C-D: But I want to draw.
Leave me alone.

M-D: Daniel, are you doing *(Mother calls from downstairs)*
something?

D-M: No! *(Daniel yells upstairs)*

D-C: Can't you just catch it
once?

*Christopher is getting agitated and starts hitting
his head with his hands.*

D-C: I won't let you draw until *Daniel places the ball next to Christopher*
you throw it in my hands.

C-D: Let me draw!

D-C: Throw one ball.

Christopher throws the ball to Daniel.

C-D: Will you let me draw *Christopher is still agitated and hits his head with*
now? *his hands.*

Individual child characteristics appeared to influence how the children reacted to the rejection and other conflicts. For example, Zachary (TD-S) was described by his mother as an emotionally sensitive child. During one visit with the family, I observed how Zachary's level of sensitivity and his fear of rejection by his brother invoked more of timidity in his behavior when considering his interactions with Blake:

Z- J: Do you want to be a monster? Me,
Mommy and Blake are monsters.

*I asked Zachary what kind of
monster I could be and ask
about Blake's opinion on the
matter.*

Z-J: He might want to be a dinosaur.

*I urge Zachary to ask Blake to
be monsters with us in an
attempt to slowly disengage
from the play.*

Z-J: You can. He might yell at me.

J-Z: What would happen if he yells at you?

Z-J: I will cry. Blake doesn't like it when I

pretend magical creatures.

Greg (TD-S) seemed to have two traits that brought complexity into his relationship with his brother. Greg's strong social skills (and Kevin's lesser ones) contributed to jealousy between the brothers. However, Greg's caring nature and sensitivity to Kevin's jealousy also contributed to his sadness around the issue. Greg shared how their mutual peer friendships were a point of tension:

They just knew somehow because he...well, even Kevin's friends like me more than him. Because I'm a lot nicer and they say, "Greg, I don't want to play with Kevin, can I play with you." I don't know why. I'm just standing around having fun. And they're like, "I don't like playing with him."

(Greg continues)

Well, I want him to have fun with his friends. I don't always want to snag his friends. But, I don't know why, they just like me 10 times better. I don't know why.

Sibling Bonds. All families (target and focus group) expressed some level of connectedness, despite the sibling challenges. This connectedness or sibling bonds seemed to be a strong, inherent force; deeply embedded in the family dynamics. The complexities of the sibling bonds were expressed movingly by Victoria (FG-P) during a focus group session. She speaks to the closeness of her children, but also the realization that those bonds may morph as they move through adolescence into adulthood:

Because I guess he wants to...he says, "I know that Emma's there for me and that she loves me." But he's aware, I guess as he's getting older, that she's not the support system or the relationship isn't quite—it doesn't have capacity that it would if she didn't have autism. And, I definitely see the, ya know, my daughter is, through my son, able to notice some of the social nuances. She sees it but she doesn't quite know how to navigate it. Like,

obviously, he goes on play dates and I allow him more freedom than she's able to have. And obviously he's relationships are different to hers and that's something that...I can't...There's nothing I can do about that. He has to be able to go and grow himself socially. But at the same time, she'll say, "Where's Paul?" I'll say, "He's on a play date sweetie. Let's go get your nails done." So, I'm kind of becoming aware of that. And I'm like, "Let's find a strategy to fix this now." And so it goes on. I'm very proud of them. I'm very proud of the relationship they do have. They are amazingly close...

Despite the periodic conflict that occurred, both the ASD and TD siblings expressed positive attitudes towards each other. This positive regard was sometimes expressed in different ways, for example, focusing on other characteristics of the sibling rather than the strength of the relationship, as Kevin did when describing his brother's strengths, "...the most energetic person I know."

For the Johnson children (especially the daughters), it was not something overtly acknowledged on most occasions. However, the affection was observed in their subtle actions. In all of the observations, the children were often seen physically sitting close to one another, comfortably laying on one another, even choosing to share seating when other open seats were available. Whereas many siblings fight over "who was sitting where first," these children often chose to sit in the same chair or be on the same couch cushion. Their closeness was further observed during an interview. Although the sisters reported constant fighting, the reality of their enjoyment of one another was seen by their actions:

Ja: Do you share a room or do you have your own?
 K: We have our own room.
 Je: Yeah, but Kimberly has a big bed. So, I used to sleep with her. But then, she keeps on snoring.

Sibling roles. Sibling interactions were also influenced by the roles that each child took within his/her sibship. At times, this seemed to be a function of their birth order in the family and at

other times it seemed related to their level of functioning. This was illustrated in numerous ways in this study. Many of the parents spoke of their TD child, regardless of their birth order, often wanting to take on more of a parental/helper role with their ASD sibling. This issue seemed to particularly resonate with several families in the parent focus group.

J: It's interesting I'll say, because Charlie's the oldest. For your two (referring to the family of Victoria and Rhonda/Calvin), they're the youngest...no...Cindy is older...Emma too...It's interesting that the two of them felt as though they were...how did they describe it? (pauses) I think they may have used the word bosses.

Rhonda (R): That sounds like Sean.

The group laughs at this phrase and the fact that the kids said it.

J: The bosses, even though one was younger. So, that was just another way all three felt like they had a lot in common. They had a lot in common, regardless. But it was just interesting to hear how they described their sibling relationship with one another. So, how would you guys describe their relationship?

R: I'll let you take that one (talking to Calvin).

Calvin (C): Um, I think you kind of touched on it. With Sean, in particular, I think he feels compelled to be the older sibling when in fact he's not.

J: Right.

R: No matter how many times you tell him it's not going to change. (Said sarcastically).
(group laughs)

C: It will be interesting to see as he gets older how he continues to operate in that realm. But, it's funny because we had a conversation maybe a week or two ago with Sean about, "We're her parents." We can hear him sometimes in the other room or downstairs or wherever the case may be. Wherever they're in the house and he'll just turn into parental mode. I think he means well. He absolutely means well. And again, I'd be curious to see how, ya know...

J: It unfolds?

C: Yeah.

- R: And I think for the fact that she's always been so small, she's just started to sprout. She's always been tiny, tiny. She doesn't look like she's 12. She looks more 12 now than she did before. So, he's always been, like, bigger than her, he's taller than her. *Calvin and Rhonda jointly mention how Sean would get confused about his role with Cindy, especially since he has been bigger than her.*
- R: Like my husband said, I don't think he means anything by it. He's even talked to his teacher about it. I think just the environment kind of lends itself to that where he wants to help her. He wants to protect her and he kind of sees those things that...it kind of lends to authority. So, I think he thinks he has authority over her. We're like, "Yeah, we have to remind him. So, is something happening, son? Do you need my help? We are the adults."
- C: "Do you need the adults?" We have to remind him.

The TD-S took on the parental role because of their relationship with their siblings with ASD..

Diane noted that her eldest son, Charlie, began worrying about his brothers at a young age:

...And, he would worry about them. He's seven or eight and he's worried about their future. So, he's very protective of them.... But um, he does very much feel like the boss. This is also, sort of, his personality. He feels very responsible and I do need to tell him, "Charlie, I know that we asked you to watch your brothers so we could do whatever. But, that part's our job. That's the parents' job and you don't need... You just tell me about it when we come home and we take care of that." He sort of...he's trying to help them catch on, fit in, fill in the blanks.

The helper/parental role was seen in practice during an observation of the Johnson children.

Thomas, the oldest, assumed the helper role with Kimberly (ASD-S) in her moment of challenge:

Thomas (T)-Ja (Jamell): This is typical of Kimberly's life—playing on the computer.

Suddenly Kimberly cries out and begins yelling at

- the computer screen. She is having a tantrum while playing the game; yelling that she can't figure out how to beat a "level" of the game. Her screaming escalates.*
- T-K: Maybe you should quit that game Kimberly.
- Kimberly quiets down briefly, but makes periodic grunts/shouts of frustration.*
- Kimberly begins to yell and scream again at the computer. She continues to escalate to the point of physically getting out of her chair and aggressively posturing as if to destroy the computer.*
- Thomas and Louis go over to Kimberly to watch her play the game. Thomas quietly stands behind Kimberly and tries to offer suggestions for how she might beat that level of the game.*
- T-K: How about you restart it and I'll do it?
- K-T: (yelling) No, I don't trust you. You're not fast enough!
- Kimberly continues to yell and scream and complain that she can't beat this level of the game.*
- Je (Jennifer)-K: Then why are you playing it?
- Father comes downstairs upon hearing the commotion. Father tells Kimberly to calm down and allow Thomas to help her figure out the game. Kimberly continues to resist. Thomas continues to try to provide hints for how Kimberly can play the game.*

On a different occasion, Mrs. Johnson commented on the helper role her children play now and will in the future, "Yeah, I always thought that once I had Kimberly that was the best thing I ever did for Thomas. And I'm glad they have each other. Someday Frank and I will be gone and Kimberly needs people that love her. And they will..." The support typically developing siblings provide in Greg's description of the help he provides his brother with the simple acts of daily life:

Umm. The main thing about Kevin is he has a lot of problems and I try to help him out, but it just doesn't work always because since he has Asperger's it's really hard for me cause....It's really cause in the mornings I give him his breakfast. I normally give him a glass of milk. Umm. I normally do everything. Kevin can do a lot of things like math and science. He's really good at learning, but he's not really good with the mornings...getting ready for school.

Theme 2: “Figure it out. You need to compromise!”: *Parental involvement serves as an interpretive lens.* Parental involvement occurred during all of the observations, either through their structuring of the environment or scaffolding through feedback. Their intervention seemed influential to how the children understood their sibling interactions. During unstructured time or “free time” not facilitated by parents, the children were often observed engaged in solitary activities, even when physically together in the same room.

Structuring the interaction. The interactions that occurred were often brief, fleeting, or arranged through the parents. Just as sibling attempts at interaction were often rebuffed so were parent interactions. This suggests that perhaps the sibling's rejections were signs of his inability to cope at that moment and not related to the person with whom he was speaking. Karen, Christopher's mother, often encouraged her sons to play together, offering suggestions of games that might be mutually enjoyable. When met with resistance from Christopher, her responses were also moments of modeling for Christopher (more appropriate ways of responding) and Daniel (understanding Christopher's rejection isn't personal):

They get quiet. Mother suggests that the boys play a game together. Daniel agrees. Mother brings out a bucket that has cars, tracks, etc. in it.

Mother (M)-C: Christopher, do you want to play with Daniel?

C-M: No, I want to draw

M-C: What are you drawing?

C-M: I'm drawing. Leave me alone

While watching TV, Christopher is repeating verbatim the script of the cartoon show. Daniel is busy playing with the cars.

Mother comes over and sits next to Christopher

M-C: What are you drawing?

C-M: Will you leave me alone?

M-C: That's not very nice. Can you say it nicer?

C-M: Will you leave me alone please?

Mother gets up and leaves Christopher to his drawing.

Scaffolding through feedback and direct modeling. Parental scaffolding was used to help foster more positive sibling interactions. It was often implemented through feedback on behaviors observed or by providing interpretation of events for the children. Karen (TF-P) utilized a lot of feedback on behaviors with her children. During the observations, her pointers were often related to helping her sons, especially Daniel; cope with his irritations around Christopher's (ASD-S) perseveration/obsessing:

C-D: Why is he wearing ___
when he's not in Egypt?

Daniel ignores Christopher

M-D: Daniel, when you brother asks you a question, you should answer him. It's rude not to.

D-C: What!

screaming

Successful coping with the more challenging aspects of the ASD was difficult for all of the siblings. Their parents' validation and ongoing education around the disorder seemed to help mediate the friction between the siblings. An example of the validation provided to Daniel by his mother is provided below:

D-M:	Trying to have him know that it doesn't have to be perfect.	
M-D:	But you know he doesn't like it.	
D:	Seven years since he's known he has autism. I just don't get it.	Daniel says this into the air in exasperation.
M-D:	No one does.	

Similarly, Karen also provides feedback to Christopher at one point in time; providing an interpretive lens that he seems to be lacking at that moment:

C-D:	Stop it Daniel!	<i>Daniel doesn't respond</i>
C-M:	I don't want Daniel to mess up the controls	<i>Mother looks over at them</i>
M-C:	It doesn't look like Daniel is doing anything.	

*They get quiet. Mother suggests that the boys
play a game together. Daniel agrees. Mother
brings out a bucket that has cars, tracks, etc. in it.*

The social modeling and emotional cueing provided by many of the parents is seen in Barbara's brief conversation with Blake (ASD-S) after he was caught tearing up Zachary's pictures:

Mother (M)-B:	Blake, do you think you're bored?	
Z-M:	(shouts from the other room) I'm bored!	
M-B:	I just wonder why you do that.	<i>(referring to ripping up Zachary's pictures)</i>

Barbara attempted to scaffold by connecting Blake's behavior to a possible feeling he had at the time. A similar type of scaffolding was done by Frank, Kimberly's (ASD child) father, when she was having a tantrum over losing at a computer game. He provided Kimberly with the emotional language to help her verbally express her frustration instead of being physical:

K-Father (F): I feel like whacking the computer in the head. Then I'll tear it up in half.

F-K: Are you angry Kimberly?

K-F: I feel like punching someone.

Kimberly postures like she's going to punch her father. He doesn't move or try to block her. She gently taps her father on the arm with her fist. There is a little smirk on her face as she does this.

K-F: Can I punch someone?

F-K: No. I'll tickle you!

Father begins to tickle Kimberly on the side and she begins to laugh. Father tells Kimberly a few jokes which seem to calm her down.

The Anderson parents utilized scaffolding through direct modeling as well as feedback during those occasions. They often encouraged the children to independently find solutions to their conflicts, like when the boys argued over which video game to play together. Prompts like, "Figure it out!" or "You need to compromise!" promoted outcomes such as what Greg demonstrated when he urged Kevin, "Let's pick a game we both can play." The parents also scaffolded their children's interactions during play episodes between themselves and their children. They played alongside their sons; encouraging joint participation and also modeling prosocial behaviors such as sportsmanship and dealing with losing. Below are two examples of this scaffolding, one during a family game of baseball and the other during a game of basketball:

Father (F)-G: Greg, don't throw so hard.

M-G: Not so hard.

Greg throws a less forceful ball and Kevin hits the ball but it's a foul ball.

F-G: Nice job Greg.

The family continues to play for several minutes. As they are playing, Greg gets upset because his team isn't able to make certain plays and is not able to score.

Kevin is pitching the ball to J.J. Kevin is having a difficult time throwing a "good ball" for J.J. to hit.

G-K: Oh my God, Kevin.
Throw the
ball!(screaming)

Parents reprimand Greg for his behavior.

M-K: Throw a good ball Kevin.
(said with an encouraging
tone)

During the basketball game, Richard praises his sons at every instance of team work with comments like, "Good play. Good passing guys!" or moments like this:

Father provides the boys with playing pointers as they play. He seems to be trying to give the boys opportunities to get the ball and shoot a basket.

After several minutes pass, there is a point in the game where Greg seems to get more competitive and is trying to get the ball more away from Kevin than the two of them (Kevin and Greg) trying to keep the ball away from their dad.

F-G: Greg, spell team.

G: T-E-A-N

F-G: That's right. There's no
'I' in team.

K-G: Wait. Greg, you didn't
spell team. T-E-A-M.
Team. You spelled teen.

RQ2: Do family attitudes and beliefs about ASD have an influence on sibling relationships?

The first research question explored the interactive nature of the sibling relationships with consideration of the influence of parental guidance. The second research question focuses on how beliefs and attitudes about ASD (both from the typically developing siblings as well as

the children with ASD) have an impact on the relationship. The family interviews and professional participant feedback provided the data for this question. Two themes emerged from the data analysis.

Theme 3: People with autism are no different than you, they just need a little help:

Perspectives about ASD matter. Overall attitudes about ASD seemed to fall into two broad categories that differed by family member: acceptance of ASD or rejection of ASD. Interestingly, these two views were not mutually independent. In fact, at times, for some individuals, they seemed intertwined. These perspectives about ASD not only shaped the sibling experience, but also the individual child's experience with his/her own ASD diagnosis. Perceptions about ASD were expressed not only by siblings, but also by parents where the parental understanding around ASD was also captured.

Acceptance of ASD was seen across families on some level. However, for some families, this acceptance might best be described as resignation or submission to the disorder. It seemed for a few families, the acceptance came in stages. The acceptance was not only around the label of the diagnosis, but also around the limitations the disorder signified, and the resulting need to modify expectations. For some parents, the diagnosis itself was easily accepted. It was the acceptance of the limitations/modifications connected with the diagnosis that was more problematic. Karen (TF-P) provided insight into the struggles she and her husband, Mike, had in accepting the challenges ASD brings:

He's (Mike) the spoiler. He's the fun daddy. He....he thinks Christopher (ASD-S) can do everything. I'm like, "He can't get dressed right. You have to help him." "He can get dressed. He can get dressed." (mimicking her husband). So, I come home and his shirt's on backwards 'cause Mike's got him dressed in morning wearing Daniel's (TD-S) pants and

they're high waters. And I'm like, "Mike, this is why you need to help him." It's stuff like that... He was in denial at first, but I think he's coming around.

Integral to this study was the perspectives of the children with ASD. In some cases, the children were not fully accepting that they even had ASD. Karen (TF-P) reported, "...well that's funny because sometimes he'll (Christopher [TF-ASD]) say, 'Oh I don't have autism. Daniel has autism!'" Other times, the children didn't discuss their perspectives directly about their diagnosis but rather around the challenges they faced, perhaps because of the disorder. For example, when asked if her diagnosis makes it hard for her to be a sister (related to her challenges with ASD), Kimberly (TF-ASD) described her challenges as connected to her sibling's reaction, "No, it's not. No, but sometimes Jennifer teases me about it." Although Kimberly didn't personally identify challenges related to the ASD, she was aware that her sister teases her about it. The implications behind the teasing suggest that there is something there to tease. Kimberly, later, described herself in a disapproving way:

Well, it's very embarrassing because I hit myself sometimes and need a lot of help with school. I'm one of the dumb ones... One of the dumb ones means I'm one of the dumb ones. I'm one of the dumb people. I need a lot of help... And...it's, like, very embarrassing. I never tell any of my friends.

Kimberly's mother, Linda, confirmed that these feelings expressed by her daughter were not fleeting or short-lived. She also touched on a common sibling desire to be better than his/her sibling, however, such competition in F-ASD may have greater implications for the self-esteem:

In fact, in this past year she's said, "I'm in the group with--whoever her aide is. I don't like being in that group. I'm with all the dumb boys. I'm the dumbest girl."...But she...Jennifer asked me, "Am I smarter than Kimberly?" And I said, "You're smart and Kimberly's

smart.” They really want to see what the pecking order is.

Similar self-perceptions were noted by Blake (TF-ASD) as reported by his mother:

I’ve heard from him in the last year is where he feels inadequate. Where he feels...he’s uses the words, “I’m really dopey. I’m a dopey kid. I have a stupid life. Things keep happening to me. So, I think he feels...he knows things are difficult for him...

Kevin (TF-ASD) was a child who expressed feelings about ASD that included negative, neutral and favorable views. Demonstrating his neutrality towards the disability, he described his Asperger’s in very factual terms, “...it’s the least severe type of autism. People with Asperger’s are able to go to a regular public school. People with autism, regular autism, will have to go to a calmer, more scheduled, more spaced out scheduled school.” When asked about how Asperger’s was for him personally, he responded more favorably, “Well, one, I’m different. Two, um...I’ve heard by having this autism thing... I’ve heard it makes you more intelligent.” Kevin indicated further that there wasn’t anything about Asperger’s that he didn’t like. However, Richard, Kevin’s father, noted that Kevin has insight into his challenges with ASD and the impact it has on others, which contributed to moments of self-deprecation:

Kevin realizes how difficult he can be sometimes. If we really work at it, he constantly wants to apologize for it. It’s to the point sometimes where he’s like, “Dad, I’m just not a good person.” And we try to get him out of that phase. But he realizes it.

Although all of the families spoke of acceptance around the disorder, how they viewed ASD itself was multifaceted. The professional participant feedback highlighted the complexities around families’ acceptance and ownership of the disorder in their families, with it sometimes being perceived as a negative issue; one to be kept secret and not discussed. One professional commented:

Some kids know a lot because their parents are forthcoming. Other times they don't have a clue. For some families the topic of the disability is taboo or they think it's not good to give the disability a name. Some parents don't like to use the word autism.

The families in this study, in contrast, took an opposite approach and openly discussed ASD in the family. The level of knowledge the children had about the disorder was reflective of the family's acceptance. The children and their parents both reported that foundational education around ASD came from the parents, sometimes followed by professional education. Parents often reported the diagnosis was shared with the children soon after they had a grasp of the disorder themselves. Karen (TF-P) told of how she initially explained the diagnosis to her boys:

I got a book for Daniel from the library... It was a sibling with autism book... And I started by reading that book. And then we just...we talk about it. When instances occur... when Christopher's having a hard time, we're like, "This is just part of autism." and things like that. But we started out with a book.

The education around ASD not only came from discrete educational episodes with parents or experts, but also from the daily experiences of living with the disorder. Paul's (FG-TD) account of how he learned about ASD is likely representative of all the families in some way, "Some of it I learned from my mom and some of it I learned from my sister."

The type of information presented to the children resulted in clear, age appropriate, understanding of the disorder, evidenced by the way in which the some of the children explained ASD. The overall level of child knowledge and understanding of the disorder was best illustrated by the responses from the sibling focus group children. They, collectively, demonstrated a mature understanding of the disorder as it related to their siblings:

Sean (FG-TD): My mom told me this. Well, my mom told me about this autism. And she told me that it is a medical condition, so it affects her brain and when she tries to do stuff, just like me, she can't quite make it.... Autism kind of is in the brain of somebody. It affects your brain. It tells your brain what you are doing. Like, you get out of control.

Paul (FG-TD): Sometimes they get it after a few years and that it's pretty hard for them because... like they don't...they know what's wrong from right but it's pretty hard for them and, like, they um ...they don't have...part of them...well, it's hard for them to make friends with people who don't have autism because it's hard for them to share.

Charlie (FG-TD): I know that it's a...that it would be classified as a birth defect in the brain. Um...I don't remember the statistics of how many it is. It affects, in my brothers' case anyway, mainly social skills not academical (sic) skills. As I know 'cause my brothers are smarter than I am in SO many subjects... Um...and it makes it hard for them to see things from other peoples' perspective. And um...to take things in a very literal manner... it's mainly social skills it affects.

Across target family and focus group TD-S, the focus group children seemed best able to articulate their understanding of ASD. Thomas' (TF-TD) simple, descriptive, explanation of ASD was common of most of the target family siblings, "Just whenever she gets excited she starts banging her knees and she has a temper. And that's it." Daniel (TF-TD) has a similar explanation, "Umm, they can't do stuff like normal people." It is noteworthy to mention that the same group of children who articulated more descriptive explanations of ASD (the focus group siblings) were the same group that also reported higher levels of patience and accommodation or compliance during play

with their sibling compared to the target family siblings. The most prominent difference between these two groups of children (TD-S) was the level of functioning of their siblings with ASD. The focus group children represented siblings with more significant impairments and diagnoses of autism or HF autism compared to the diagnosis of Asperger's Syndrome of the target family ASD-S. This distinction between the target family and focus group siblings is important to consider and will be discussed in chapter 5.

The knowledge, understanding, and acceptance of ASD (from both the TD-S and ASD-S children) contributed to their perspectives around their sibling relationships. The understanding of ASD expressed by the FG-TD siblings seemed to be connected to how they viewed the locus of control of their sibling's behaviors (e.g., internal—"You are irritating" or external—"Your ASD behavior is irritating") and their openness towards their sibling. For example, Sean (FG-TD) demonstrated an understanding that despite his sister's behaviors towards him, she cares about him, "She'll keep on yelling, yelling. Get in my face. But, I still like it because she's very, very playful and...well, she does love me." Kevin (TF-ASD) expressed well the general tone of the families around ASD and its effect on the child and the way in which they responded to it:

um...doesn't mean that you're worse than anybody else. It doesn't mean that you're better than anybody else. It just means that you're different...That people with autism are no different than you, they just need a little help. They may be smarter, or not as smart as you. Just know that, um, they have some difficulties around some things and that you should help them all through it.

Theme 4: "I'm not a fan of ASD": ASD brings complexity to the sibling relationship.

The complexity of reactions and sentiments that ASD brings to sibling rapport is seen in the range of emotions experienced by both in the pair. Consistent with the literature on sibling adjustment

and coping in families of children with disabilities (Giallo & Gavidia-Payne, 2006; Nixon & Cummings, 1999; Rossiter & Sharpe, 2001) the children in this study showed feelings alternating from sadness, to anger, to frustration, to confusion, to pride. There was a sense of conflicted emotions and the inconsistencies between the love for the person (ASD-S) and the dislike of the diagnosis. The children with ASD did not indicate any strong adjustment or coping challenges related to their sibling bonds nor did they specify any deficiencies in their sibling relationship outside of the typical teasing that occurs between many siblings.

Dislike of the diagnosis. The dislike of ASD expressed by children was often related to either: 1) confusion around the disorder; or 2) a combination of frustration (with the behaviors characteristic of ASD) and sadness over the loss of strong connectedness between siblings. Most evident in three for the target family TD-S were feelings of sadness and loss around a brotherhood that was not going to be. Karen (TF-P) shared how Daniel (TD-S) often expressed sadness around the rejection from his brother, “He often says, ‘Christopher doesn’t love me.’ or ‘Christopher hates me.’... I think he [Daniel] just feels like he doesn’t have that brother.” As discussed in earlier themes, feelings of rejection was another common feeling shared by the typically developing siblings. Rebuffs by their siblings and feelings of rejection were commonplace for the TD-S. Hurt feelings were evident and expressions such as Greg’s (TF-TD) were often heard, “He never wants to play with me.” There were several instances where the ASD-D displayed a lack of interest in his sibling despite the bids for attention. One of the professionals (P5), a therapist and former disabilities case manager, summed up the loss that these siblings may experience:

The siblings often reported frustration, jealousy, a desire to make them [ASD-S] better...and a desire to have a close relationship. But due to the nature often of the disabilities their siblings have, it couldn’t be a typical relationship. With that, they often had to grieve the

loss of the desired relationship.

The challenge most often referenced by the siblings was their frustration around the “ASDness” in their brother or sister. The issues around perseveration and tantrums were often mentioned as being the main source of their irritation. Sean’s (FG-TD) description of his frustration with his sister’s behaviors is demonstrative of the type of comments the typically developing siblings often made about their siblings, “Sometimes, my sister will go way over the top and she’ll start to get out of control and that’s when she starts really getting on my nerves.” Although Sean indicated awareness that these behaviors are related to the ASD, he stated what other siblings echoed, “My sister also comes to me mad. Tries to pinch me, bite me. And it’s not gonna end good for her either.” Parents also reported that an additional frustration felt by the TD- S was the all-consuming nature of the ASD on the family life. Barbara (TF-P) described it this way, “But, it seems to me like sometimes Blake is this overwhelming force that just permeates the entire house; the entire family.” She went on to describe how Zachary (TD-S) struggled with finding his own space and identity in the house. Interestingly, Zachary also pointed to an issue not addressed by the other families—the frustration experienced by the ASD-S. Zachary, himself, spoke to the strain that is experienced in these relationships and demonstrated recognition that the challenges are bi-directional. When asked about the challenges about being a brother he shared, “Mine is dealing with my brother.” When asked to guess how his brother would answer he responded, “Um...Me... Uh...the way I act when I want to play something. He always yells at me.”

Embarrassment is another issue many of the siblings mentioned. The tantrums and unexpected behaviors are what the siblings noted as the source of their embarrassment. One family support worker shared. “They report being embarrassed when they are in public with the sibling and the sibling misbehaves.” Parents noted that the embarrassment slowly emerged as the children got

older, similar to what Rhonda (FG-P) described, “But I think as he’s getting older, he’s getting more...just like sometimes, ‘Mom, that was embarrassing what she does.’ Or, ‘What she just did was embarrassing.’” One support worker (P6) shared a similar finding, noting that the embarrassment of the disability emerges slowly as they (TD-S) begin to have a better understanding of the disorder, “The 5-7 year olds are just starting to notice the disability in their brother or sister and do not yet feel embarrassment or feel their family is ‘different’ from other families.” Perhaps as this feeling emerges, it begins to extend to other areas of the child’s life as described by a family support worker (P3), “They report being embarrassed to have friends come over.”

The need for accommodation was an important aspect of sibling dynamics. The typically developing siblings noted that most of their joint playtime with their sibling was orchestrated by the ASD-S, on his/her terms. This dynamic was a source of frustration and imbalance in the relationship. Greg (TF-TD) spoke of the unevenness of the give and take with his brother:

I’ll let him play his game with the Wii. Um...I’ll do what he wants to do... I always have to do MY own thing. ... Because it’s really hard for me and my mom always has to tell me, “Be nice to Kevin because he’s trying to learn to be nice to everyone that he’s around.”

The resentment towards the accommodations needed is not just in reference to the type of sibling interactions, but also towards the impact it has on family activities. All of the professionals made reference to the limitations of family outings, similar to this comment by a therapist (P2), “...Hard to go places together because the child with ASD often gets upset: no restaurants because of the noise/colors/other sensory issues.”

Love for the person. While all of the children expressed some level of frustration in their sibling relationships, they also clearly articulated an enduring desire for companionship with their

brother or sister. Victoria (FG-P) shared how her son's love for his sister and his persistence to engage with her helped to solidify the bonds that they currently have:

He was persistent—"You are going to engage and play with me. You are going to be interested in this or that. I'm going to tell you about it and I'm gonna talk out. So, you're gonna hear model talking around. 'Cause I'm gonna talk at you even if you are not involved."

Victoria also stressed that the love between TD and ASD siblings is mutual, even if it is structured less traditionally. She told of how her daughter shows her love for Paul (TD-S) through her actions:

...especially as they start to get older, she'll do stuff for him. So, it's nice to see her be able to give back. My daughter's pretty good at regular self-care and all that kind of thing. And, you'll see her wiping his face or putting out his clothes or tidying up his stuff behind. So, it's nice to see that there is some give and take in that relationship.

Charlie (FG-TD), irrespective of the challenges he faces with his brothers, showed a profound sense of pride in them and captured the contradictions and challenges of having siblings with ASD:

It's rewarding to see smiles on their faces, but, ya know when they've done something really good they feel proud of themselves. But it's also challenging when they refuse to listen to you or when they're having one of their bouts of...

Based on her work with siblings of children with disabilities, a family support worker (P6) noted similar expressions of pride made by siblings, "They [TD siblings] love them, they are proud of their small steps of accomplishments. They definitely keep their sense of humor about the disability and silly things they find themselves doing to keep their brother/sister calm or happy." Another family support worker (P4) noted how the siblings are able to find ways of connecting, "They wish

they would be able to do more things together, like other people do with typical siblings. But they have their own special play and routine they go through, and enjoy doing that with their siblings. They admire their special gifts...”

Humor was a coping strategy that many families indicated they used in trying to survive with the challenges of everyday life with ASD. Rhonda and Calvin (FG-P) made the point that, as a family, they had to learn to have a sense of humor about some of the hurdles they faced, “...we used to say when she was little—you learn to laugh.” They commented on the challenges of the invisibility of autism and the expectations people have based on outward appearances:

The child with Down Syndrome, you instantly know—okay. But a child with...they look like everybody else. So, we could be walking together somewhere and she’s cute and everything. And all the sudden she’ll look and “Ooh blab la” (Rhonda imitates Cindy making an unexpected noise). People are in shock and we’re like, “Yeah.” We have to be able to laugh because she’d scare people with some of the things she’d pull from out of nowhere. And then we have to be able to laugh.”

This was one strategy parents encouraged their children to embrace in accepting they have no control over these behaviors. As Rhonda says, “Yeah, sometimes things are gonna happen.”

Conflicted emotions. The conflicted emotions shared by many typically developing siblings were identified consistently across the professional participants. One therapist stated (P5), “The siblings seem to experience conflicted feelings between the love they have for their sibling; trying to be considerate and compassionate to their siblings, but also the desire to have more of their parents’ time and energy.” Many of the professionals indicated the jealousy around sharing of parents’ time as a significant factor in the conflicted feelings siblings experience. A family support worker (P3) noted, “They [TD-S] report wishing that their parents had more time to spend with

them. They complain about having to spend so much time attending their sibling's various therapies."

Some of the conflicted emotions faced by TD-S are related to their confusion of the disorder. One professional (P5), a therapist, commented, "Typical siblings overall say they love their sibling with ASD but often don't know how to deal with their behaviors." She also noted that this is not unique to the TD-S, "The child with ASD also feels confusion, for different reasons, with their typical siblings because of their limitations with understanding."

Parents reported that their children's conflicted feelings about their sibling seemed to appear often when peers were involved. They noted the dilemma their typically developing children face when wanting to be liked by their friends, but also feeling the need to stick up for their sibling when others are making fun of him. The siblings handled such situations differently. For example Greg (TF-TD) was reported as often finding the courage to correct his peers as described by his mother, Jane:

...and Greg would say, "Mom, you'd be proud of me." He goes, "One of the kids was teasing Kevin and I looked over and said, 'You need to stop! That's my brother and you need to stop.'" ... And I said, "How does that feel?" And he said, "It felt good."

Other siblings found it harder to disengage from participating in negative actions toward their sibling, instigated by peers. Barbara (TF-P) spoke of her son's dilemma during a joint play date between Zachary (TD-S) and Blake:

Yeah, there's one girl that came over whose kind of a, I don't wanna say bully, but she's really high strung. Sometimes people make bad decisions when they're with her.... So, there again we had to have discussion about, "We don't...ya know...We're not excluding people and it's not okay to gang up. And it's not okay to..."

Zachary's experiences were typical of many of siblings, according to the professionals. One child therapist (P2) told of the angst siblings experience, "Embarrassment in front of friends, wanting to protect their sibling but also being embarrassed by him and wanting to join with the teasing. If the sibling joins in teasing, he often reports feeling shame about it..." This type of pressure from friends was also shared by Greg as well. The social inadequacies of his brother, Kevin, presented problems in their joint friendships. Greg shared how he often feels the pull from both sides:

And he does have trouble, like, when friends get mad at him downstairs, they'll whisper in my ear, "Can we stop playing this? Let's go ditch him..." So, I'm like, "No, I wanna play." 'Cause I really just want to be nice with my brother.

The conflict referenced by the professionals, a love-hate dynamic, was supported by Linda's (TF-P) description of the relationship between her daughters, Kimberly (ASD-S) and Jennifer:

I think they love each other. I think that she [Kimberly] gets on everybody's nerves some too. And then they push her button because they are so easy to push. And Jennifer just can't let it go. .. And then today she [Jennifer] said...Kimberly was at camp and Jennifer was with me and she said, "I miss Kimberly." And I said, "You should tell her that." She's like, "Because I like to tease her, and..." But I think deep down, um, yeah she does love her.

RQ3: What factors contribute to parental decisions to access sibling support services?

The first two research questions touched on the interactions and dynamics in sibling relationships in F-ASD. The final research question explores the factors related to parents' decisions to seek out or decline/postpone support services for their children (and families). The parent interviews and the feedback from the professional participants are the primary source for

this information. Based on these accounts, one theme emerged during data analysis for this question.

Theme 5: It takes a village: *Community resources and supports provide acceptance and education.* For many of the families, the decision to access community supports and services was one still in process. All of the children with ASD (target and focus group) were already connected to school-based special education services. Many of the parents had also begun exploring and/or obtained additional intervention services for their child with ASD such as: speech therapy, occupational therapy, therapeutic recreational programming, and social skills intervention. Four families (3 focus group; 1 target family) either currently had or were in the process of securing mental health services (i.e., individual therapy) for their child with ASD.

These mental health services were initially sought for issues surrounding the ASD and their child's social challenges versus family-centered services. However, the Anderson family did choose to utilize Kevin's (TF-ASD) mental health provider to deliver time-limited sibling sessions during a period of intense sibling conflict.

Most of the target parents seemed to approach the decision to access support services based on their level of *current need* as opposed to a proactive stance. Those families who had accessed supports (currently or in the past) noted seeking out the services due to the urgency of first learning of their child's diagnosis. In many cases, the services sought (at least initially) were intervention services for the child with ASD. The second type of services parents initiated were "non-intervention" types of community supports such as parent support groups or psycho-educational supports (i.e., workshops on ASD). Generally speaking, overall family functioning concerns were not the impetus for seeking services. Rather, it was information seeking. This was the case even though they all acknowledged sibling conflict was a significant issue in their families. The most

common type of support referenced was the use of informal supports. Karen (TF-P) explained how her friends and colleagues serve as an informal support network for her, buffering some of the stress she experiences:

Yeah. It's kind of like I don't feel that bad about it... And the person I work with has a son with Fragile X syndrome, and they're [the kids] very close to kids with autism. So, we're always....she's a support for me. ... Yeah. I might some time, but...maybe when middle school comes I will be, but...I do have support, it's just not a formal group or something.

Richard (TF-P) expressed a similar sentiment:

Yea, he goes to Sibshops [sibling support services]... That helps out. There's some things in place. A lot of it....it's not like it's bad enough that you need extra help or need services. It's just basically changing your lifestyle to accommodate for it.

Although the families' informal community supports were described to be sufficient for them at this time, they also acknowledged the possible future need for additional formal supports. During an interview with Barbara (TF-P), she acknowledged that Zachary (TD-S) may, in the future, need his own support:

...that's something that comes up from time to time where I've thought maybe that would be a good thing. Someone for him to talk to about the difficulties that he has. So, yeah that's something that's under consideration.

The availability of appropriate services and supports was another factor in families' decisions around seeking out and utilizing services. The appropriateness of services for Kevin (TF-ASD) was a particular challenge for the Andersons. The father recounted:

In one instance, she signed him up for...got him involved in Sibshops and the Arc and all that and he went to a baseball game for special needs kids through the Arc. And we got

there, and Kevin didn't realize it, but every kid there...probably 90% of them were severely mentally retarded. And a couple of them were pretty mentally retarded and then there's Kevin... My concern was, "Jane, this isn't him. I think this is going overboard." So, we talked about it and she decided to pull him off of whatever. ...with the Sibshops, most of the kids' siblings that are there have a lot more severe issues than what Kevin has. But, Greg's okay with that. My concern was Kevin, looking around and being like, "Why am I here with all these kids? These kids are reading on a 2nd grade/2 year old level? Why am I here with them?" But we talked about that, especially with the softball team. And I was like, "I just don't think that's the place for him." I think he maybe went to one game or two games or something. But they were cool with it. I don't know if they were like, "Hey, this kid doesn't belong here."

The level of community *acceptance* of their child (with ASD) and family also emerged as a salient factor in the overall family coping and adjustment, and influenced their perceived need (or lack of) for additional support. For the Taylor family, the unexpected gestures from the neighborhood/local community, demonstrating their acceptance and love of Christopher (TF-ASD), was integral in building the esteem of the entire family. Karen (TF-P) spoke of how her community seemed to embrace Christopher. She shared how Christopher was loved by many at school and elsewhere, and was indeed quite popular, "...we have a very good community at Christopher's school and classmates. It's helped us so much because we're not ...I mean nobody dislikes Christopher. In his class, all the boys love him. ...Every kid loves him. They all help him. All the parents all accept him." Karen gave a poignant example of how the small gesture of kindness

helped her family feel accepted. Karen told of a time when Christopher participated in a talent show and experienced stage shock and was supported by a classmate:

So he got up there and he freaked. He was like, “Help, help, help.” And the same mother said to her little girl, “Go up there and sing with him.” ‘Cause no one wanted to sing with him ‘cause they didn’t want to sing...it wasn’t that they didn’t want to sing with him... And so the little girl came up; grabbed another microphone. She started singing and then they both started singing and it was awesome. So, like... it’s that. That’s the stuff that’s helped us; gives us peace of mind to send him on the bus; to have him in school.

The experiences of the Taylor family demonstrate how the perspectives and acceptance shown by the community can have a strong influence on the way in which the family perceives their situation. For example, Christopher’s brother, Daniel, was described as jealous of his brother’s popularity in the community. According to his mother, Daniel did not experience the same level of overt admiration from the community (although he was also warmly regarded). This, along with the other coping/adjustment factors for Daniel, contributed to some of the sibling strain. However, coincidentally, during the data collection time frame, there was an instance where the positive attitudes expressed towards Christopher had an equally positive impact on Daniel’s perspectives about his brother. Documented in a field note was this summary:

She [mother] also noted a second incident recently where Daniel told his mother that a child said to him, “You’re Christopher’s brother? You’re so awesome ‘cause you’re his brother.” Mother reported that Daniel was so excited to be told that he was cool because of his brother. Mother noted that this was the first time he saw having Christopher as a brother as positive. Usually it’s “I hate him.”

In this instance, the community acceptance was integral in increasing the sibling affiliation expressed by Daniel. Diane (FG-P) also noted how the community's acceptance of her triplets with ASD supported positive outcomes for her son Charlie (FG-TD), "But, he discovered when he brought friends over; the friends were just charmed by them. The friends really liked them. So that, fortunately, didn't end up being a negative socially that way."

Through the parent interviews, it is evident that community supports were valued as needed by all of the families. The type and level of supports needed, at any given point in the families' lives, varied. However, one parent summed up well how these F-ASD will find success. Diane (FG-P) stated:

.... We have wonderful godmothers who are very involved with them. And um, we have a lot of help, especially in the early years. It takes a village. I told them it's gonna take a music ministry—a choir and the bell choir.... It's gonna take more than a village. It's gonna take the entire Parish.

The third research question was of an exploratory nature to see how families utilize sibling support services. It was found that these families, as a whole, did not utilize these supports. Generally, it appeared that sibling support and related services were major factors for these families because they had adequate informal supports available to them (i.e., co-workers, classmates, and the community at large) which provided them with acceptance and understanding. Irrespective of these findings, it was important for this question to be asked, for if not, it would not have been realized that formal supports were not of significant value to the families at this time.

Summary

The six themes that emerged from these three research questions were discussed in this chapter. The questions queried the nature of sibling relationships and parental influence on those

relationships in families of children with ASD. In addition, the questions also explored if and how family attitudes and beliefs about ASD influenced these sibling relationships. Finally, the third research question touched on the decision-making process for accessing or declining services for their family. Further discussion of these themes is provided in the final chapter.

Chapter 5: Discussion

In this study, I examined sibling relationships in families of children with ASD, with a focus on how the disorder shapes these relationships and how parental influence contributes to those sibling relations. The Circumplex Model of Marital and Family Systems and the Transactional Model of Development (Olson, 2000; Sameroff, 2009) were the theoretical models that helped to frame the data and served as an interpretive lens during data analysis. The themes that emerged from the participants' personal narratives centered around an overarching core perspective, *Family life as usual: Family life continues but with adaptations*. The connecting subthemes demonstrate how this is applied in the families' lives.

Inferences from Findings

The findings from this study highlight the unique aspects of sibling interactions in these families. Whereas this study uncovered similarities between F-ASD and those of families with children without ASD, it also underscored the unique issues faced by F-ASD. Several important findings warrant discussion.

Family Life as Usual

The central finding of this study is that despite the unexpected disruptions and stressors that accrue to the family with the diagnosis of ASD, family life does continue as usual, albeit with adaptations. Drawing on the Circumplex Model (Olson, 2000), the families' level of flexibility allowed them to find their equilibrium (through these adaptations to family life) even after the initial shock and potential disequilibrium of the diagnosis. The parents all indicated, in one way or another, they tried to have their children lives be as "normal" as possible in the midst of their

challenges with ASD. Many of the families approached this task with an attitude of full acceptance and integration of the diagnosis into family life.

The parents talked of continuing on with the normal routines, with an awareness of possible modifications. One way in which the parents attempted to establish calm and normalcy in the family was in the organization of their family activities. In part, due to the differing interests and abilities of their children, many of the social-recreational activities of the children were done independently of one another. In other words, much of the weekly activity tended to split the family, with parents divvying up responsibilities such as driving. This type of transportation arrangement is not atypical for many families. However, the underlying compelling reasons for these arrangements in F-ASD were out of necessity rather than convenience. The parents spoke of behavioral meltdowns or other challenging behaviors that had a negative impact on the extra-curricular activities of other family members. Similarly, parents shared that the level of supervision and time commitment needed for the ASD-S limited their availability for the other children's activities. Linda (TF-P) expressed this decision making process well, "...lots of our activities are what Kimberly wants to do...She dominates a lot of the decision making. ... In terms of decision making things, sometimes it's just easier not to fight with her." Barbara (TF-P) stated similarly, "A lot of the family life revolves around accommodating him or trying to work with him through stuff." Parallel to experiences of families described by Hutton and Caron (2005), the study families talked about the necessity to do extensive preplanning for family activities; taking into consideration the ASD. They reported needing to make alterations to their family outings based on whether the ASD-S could fully and happily (i.e., without meltdowns) participate. At times, this meant reduced vacation time or a limited vacation experience.

Involvement

The main finding related to sibling interactions and involvement was that their ASD-TD sibling dynamics were similar to TD-TD sibling pairs (Kramer & Kowal, 2005; Ostrov et al., 2006) but with unique qualities. Common to all of the families was a sense that ASD intruded on the sibling relationships. The behavioral presentations of the ASD that seemed to have the greatest impact on the sibling relationships were: perseverative behaviors centered on unique/intense interests, tantrums, rigidity, stimming, and social deficits/missing social cues behaviors. These particular behaviors contributed to the type and level of involvement between the siblings; sometimes impeding mutually enjoyable interactions. Perseveration behaviors were a barrier to sibling connection. When this was the dominant trait in the ASD-S, it created a distraction and contributed to exchanges that were often brief or fleeting. When the TD-S did not share the same interests, the perseveration was not only a source of aggravation for the siblings, but also a cause for rejection from the ASD-S. In several of the families, I observed the ASD-S reject bids for engagement from the TD-S because of the perseveration, or because the TD-S wanted to do something that was not of interest to the ASD-S. Without parental intervention in these situations, the children did not connect and engage in joint activities.

The sibling involvement and engagement of these children cannot be discussed absent of the parental contribution. Parental guidance was paramount for all of the sibling pairs. There was some level of parental involvement observed with all of the target families. The parents not only served as an interpretive lens for the children, but they also helped to structure the sibling interactions and/or scaffolded either through direct feedback or modeling. Without the structure parents provided to the play, the children often had difficulty organizing their play and finding mutually enjoyable activities to do. Parents provided feedback to the children related to behaviors

they observed in their exchanges, which were often strained. During times of frustration and confusion, parents were seen providing and modeling coping strategies; helping to foster more positive interactions. Their assistance helped to increase the chances of prolonged engagement between the siblings. Parents often served as a translator for the children through their direct modeling of social exchanges. The target family parents were often observed directly playing with the children, primarily serving as a mediator of sibling conflict.

Conflict

Conflict was a part of the sibling relationships. On the surface, the conflict looked to have many similar qualities to that of typically developing siblings: for example, teasing, and instigating,. However, there was a unique underlying aspect to the ASD-TD siblings' conflict—the ASD. For example, the TD-S' desire for interaction often led to forced or instigated interactions with the ASD-S; potentially creating conflict. The effort for connection was often met with rejection by the ASD-S, who had little to no interest in their topic of play. Even in times when the siblings found a moment of mutual enjoyment, a misreading of a social cue by the ASD-S could lead to the dissolution of a positive play episode. These types of situations led to confusion and frustration for everyone. While the ASD influence stood out as the predominant contributor to sibling relationships, it is important to note that individual child characteristics were also influential. These characteristics not only influenced the traits that each child brought into the relationship, but also influenced how each child responded to the particular circumstances. Typically developing siblings who were more competitive in their play (such as Greg in the Anderson family) had more times (albeit short-lived) of arguing during play. Conversely, children (both ASD-S and TD-S) who were more socially interactive were more likely to pursue and/or welcome sibling interactions even if the particular theme of the play was of less interest.

Sibling interactions varied based on the type or level of functioning of the sibling with ASD. One surprise in this study was that it was not unusual for the TD-S to have trouble understanding and showing empathy for the challenges faced by the ASD-S related to misreading more subtle social cues. This was the case for the Anderson and Johnson siblings. In children with more significant autism, the social impairments were greater and therefore more easily recognizable. Thus, the former mentioned sibling interactions were more reminiscent of typically developing siblings and less so with sibling pairs where one had a more significant disability. On the other hand, when the characteristics of ASD were more pronounced with a lot of perseveration and stimming, the differences in the sibling interaction styles were more apparent. Interestingly, the level of conflict between these two groups of siblings was similar. It is possible that the TD-S of the children with Asperger's Syndrome/very high functioning autism had a harder time distinguishing which annoyances were ASD-related or not. This may possibly lead to greater irritation if the TD-S interprets the behaviors as those which their sibling can control but just chooses not to (Begun, 1989; Benderix & Sivberg, (2007; Chambres, Auxiette, Vansingle, & Gil, 2008; Huws & Jones, 2010). On the other hand, while the TD-S of children with more visible impairments may understand the connection between the behaviors and ASD, the nature of the behaviors may still create frustration; also leading to conflict between siblings. However, these particular behaviors (e.g., stimming and perseveration) seemed to present more barriers to the sibling interactions than did the subtle social impairments that were seen more often in the siblings with Asperger's Syndrome.

Sibling Roles, Bonds, Adjustment and Coping

Sibling adjustment/coping and sibling connectedness seemed to be intertwined and mutually dependent in these families. It is unclear which influenced the other, but it seems as though the TD-

S who had the stronger sibling bonds seemed to have more positive or neutral perspectives about and adjustment to the ASD and related issues (and vice versa). Notwithstanding, frustration, confusion, and sadness were consistent emotions shared by the TD-S. This is consistent with previous studies on siblings [adjustment] of children with disabilities (Giallo & Gavidia-Payne, 2006; Kaminsky & Dewey, 2002; Nixon & Cummings, 1999; Rossiter & Sharpe, 2001). As noted, the emotions experienced by the siblings were directed towards the ASD behaviors rather than the ASD-S themselves. It is important to note that the child with ASD likely had coping and adjustment challenges as well, even if these were not articulated as clearly during my observations and interviews. However, reports from parents and my own observations included evidence that ASD-S may have had feelings of jealousy and anger towards their TD-S. For example, parents spoke of the noticeable differences between the social abilities of their children and the underlying jealousy or confusion the ASD-S often had related to this realization. Indeed, ASD siblings were, at times, frustrated by their interactions with their typically developing siblings. Christopher (ASD-S) demonstrated this frustration when asked/forced to engage in play at undesirable times and /or with undesirable themes of play.

A couple of the children in this study also showed signs of internal adjustment/coping challenges with their diagnosis. In two families, low self-esteem issues were a part of the child's processing of the diagnosis. Both children spoke of feelings of inferiority with words like "dopey or dumb." While not directly observed in sibling interactions, it is not difficult to assume that the children's understanding and interpretation of their diagnosis influences their self-perceptions and consequently lends challenges to their interactions with siblings.

Children's levels of understanding and perspectives about ASD seemed to moderate adjustment and coping. While all of the siblings had some knowledge about ASD, their verbalized

level of understanding around the disorder varied. All of the children could describe the specific behaviors of ASD associated with their sibling. However, only some of the children showed a clear, age appropriate, grasp of ASD. These children seemed to have the stronger bonds with their siblings and were reported by their parents to have fewer negative adjustment issues. Similar to experiences reported in studies of siblings of children with disabilities (Huws & Jones, 2010) the siblings of children with less severe ASD may have held a different perspective of their siblings' behaviors than the siblings of children with more overt ASD-like behaviors. As noted earlier, the target family ASD-S' were generally diagnosed with a milder form of autism and had less severe behavioral traits of ASD than the children represented by families in the focus groups. For the target families, the direct connection of the ASD-S' behaviors to ASD was likely less obvious. Even though these behaviors were less overt, a downside of this is that the TD-S may have seen the sibling as annoying versus the behavior as annoying and giving them "a pass" due the disability. Conversely, the FG-TD siblings had brothers/sisters with more significant and noticeable impairments related to ASD. Thus, it may have been easier for these siblings to associate the behaviors with the diagnosis and offer greater understanding and accommodation to their siblings' requests and needs. If this supposition about the TF-TD and FG-TD siblings is correct, it would be consistent with other studies (i.e., Chambres et al, 2008) which found that understanding a disability generated more acceptance. This research has also demonstrated that people tend to have lower expectations of the child with disabilities once they learned of the diagnosis. This may suggest that the focus group siblings didn't expect their siblings to behave "better" and, therefore, had more positive perspectives around the behaviors than did the TF-TD siblings. There are both positives and negatives to this, however. On the one hand, the FG-TD siblings may be more understanding, but on the other hand they may doubt their siblings' abilities.

A transactional-family systems perspective would suggest that the family attitudes about ASD have a bi-directional influence. While the parents in this study acknowledged the challenges for their families around the ASD, their approach to the challenges was not one of “deficit” where they focused on the disruption the disorder brought to their family. Rather, similar to what Stainton and Besser (1998) reported, these families demonstrated resourceful ways to adapt to adversity. The parents’ perspectives about the impact of ASD on the family seemed to match the children’s attitudes in many ways. All of the participant families openly talked about the diagnosis with their children. Some families integrated the diagnosis, and the continual education around the diagnosis, into their family life; others, less so. When the children had a working knowledge of ASD, it seemed that their frustration was more tempered and specific to individual events versus having a more global frustration with their sibling. Likewise, per parent report, when the children with ASD demonstrated understanding of their challenges, they seemed more open to acknowledging their role in sibling conflict. Even with the more “negative” aspects to sibling adjustment and coping, there were strong signs of sibling connection and positive regard. During moments of joint play, there were observations of mutual enjoyment. During moments of need, siblings provided support.

The Johnson family added an extra element to understanding the sibling bonds. In this family of four children (2 boys and 2 girls; boy-girl, girl-boy order), signs of a possible gender contribution were seen. Per the family report (both child and parent), the gender versus age aspect seemed to be the stronger pull for the sibling pairings. In this family Kimberly and her sister had the most conflict, which did not seem associated to the ASD. This sibling dynamic was not dissimilar to other families where siblings of same gender may have more conflict, especially if close in age (possibly due to gender related commonalities and competition). Although not especially apparent for the Smith brothers, the twin bond (or lack thereof) may have also been a

factor in the deep sadness expressed by Zachary (TD-S) about his brother's rejection towards him. As his mother noted, "...there's never been a time when they've been without each other. So, that's kind of an interesting context." Perhaps the rejection by his brother was felt more deeply by Zachary given their unique circumstances.

Formal and Informal Supports

Supports were utilized and seen as helpful by all of the participant families. However, the families as a whole seemed to access their informal supports more readily than formal services and supports. While some of the ASD-S are/were in formal treatment, this level of support was not often utilized for sibling or family support purposes. The accessibility to community activities and the acceptance by the community seemed to be the most needed level of support at this point in time. Several parents recognized the possible need for increased formal sibling and family supports in the future. The families' ability to adapt to the challenges faced by the ASD seemed tied to their perspectives around the disability and the level of support found through their informal networks.

Limitations and Contributions

Limitations

Though this study contributes to the growing knowledge base on ASD and families, the findings of this study should be considered in light of a few methodological limitations. First is the number of family participants. Although not uncommon in qualitative research, I had a small number of target and focus group families. With such numbers, it is more difficult to ascertain how common the reported experiences are to other families of children with ASD.

Due to self-selection, it is important to note that the families in this study may not represent the typical families of children with ASD. The families who volunteered to participate may have had an investment in understanding ASD, uncommon to other families who did not participate, and

availed themselves to the study. The use of convenience sampling is a limitation which presents the potential for a skewed or biased representation of the issue.

Even though triangulation activities of this study provided additional perspectives and revealed commonalities between the groups of participants, no statements of causality or generalizability are appropriate. However, qualitative research does offer the opportunity for the generation of inferences (Lewis & Ritchie, 2003—cited in Daly, 2007). Moreover, in contrast to generalizability statements seen with quantitative investigation, qualitative inquiry can provide “transferability” of findings (Lincoln & Guba, 1985). Thus, it can be said that the experiences described in this study may be similar to other families of children with ASD. The narrative analysis of the interviews allowed for repeated patterns and storylines to emerge. Collectively, they helped to provide a fuller picture of the experiences in sibling relationships in these families—with potential transferable aspects to the larger overall group of families of children with ASD.

Relevant to transferability of findings, a third limitation to this study is the focused selection criteria related to the verbal functioning level of the children with ASD. This criteria lead to a sample of children who are on the “higher functioning” end of the autism spectrum. While this fairly homogeneous sampling allowed for an in-depth look into families and siblings of children from this diagnostic group, the findings can only be discussed in relation to this group and not the broader autism spectrum. Additionally, although an operational definition of ASD was established for this study, there are still subtle differences between the triad of diagnoses that make up the construct ASD. Thus, it is impossible to fully apply the findings of this study to any one of these three diagnoses alone. This challenge is difficult to eliminate when the disorder itself (termed ASD) has gray distinctions between diagnostic criteria.

Two other limitations that merit mention are: 1) the researcher's influence on the study, and 2) the unavoidable researcher bias. In my role as a "reactive" participant (Cosaro, 1985), I made every attempt to make my interactions brief with the children and only respond to their initiations of contact. However, there were a couple of instances where this was a challenge. With three families, there was at least one instance with each family where the children pursued prolonged engagement with me (e.g., requiring at least 3 verbal exchanges). This level of engagement with the children did not seem to be a detriment to my role in the research, however, it did allow for a stronger level of rapport with the children. This may have allowed for the children to feel more comfortable in my presence. It is possible that these researcher-child interactions may have influenced the information shared by the child(ren).

Related to researcher bias, the findings presented are based on my personal analysis of the data and identification of themes. Steps were taken to reduce this personal effect, but it is impossible to eliminate all of the influence of bias on the findings. However, as discussed in earlier sections, I engaged in verification activities (e.g., peer debriefing) as further attempts for checks on interpretations.

A sixth limitation of this study is the lack of opportunity to investigate the intersection of culture into family dynamics. As noted earlier, this study was not an attempt to do representative sampling for which there would be more diversity between participants. The most in-depth work was done with a racially homogenous group of target families (Caucasian) with similar religious backgrounds (Judeo-Christian). Beyond culture (i.e., ethnic or racial background) more research is needed focusing on beliefs, attitudes and responses to the ASD, as it related to the sibling relationship, looking at religious affiliations and also socio-economic levels.

A final limitation was the low participation of fathers in this study (50%-target families; 25% - focus group families). Based on the information gained from fathers who did participate,, it was evident that they play a significant role in the lives of their children and have an influence on the sibling relationships and interactions. Additional insight might have been gained from perspectives of these fathers. It is noteworthy, however, that the observations of father-child interactions with the Johnson and Anderson families and the interviews with the fathers [Richard (Anderson family), Calvin (focus group), and Sylvester (Smith family-initial face-to-face meeting with families)], provided a glimpse into the interactive role fathers play in shaping their children's sibling relationships. The lower participation by fathers was, in larger part, a consequence of the time constraints of this study and the fathers' limited availability related to scheduling needs that existed for families, which is consistent with previous research on family interactions in general and certainly not specific to this population.

Contributions

My research contributes to a greater understanding of the experiences of families who have a family member with an autism spectrum disorder. While ASD is a burgeoning topic, how it shapes family relationships is uncharted territory. My study contributes to the research base on ASD and sibling relationships and expands our knowledge about: 1) the bidirectional influence of ASD on family outcomes; 2) the influence of parental support on sibling interactions (i.e., the sibling relationship); and 3) the consideration of ecological factors (i.e., community supports, resources, and education around the disability). This research has the potential to advance our understanding of the sibling relationship and experiences in families of children with ASD from the perspectives of both the child with and without ASD. By including the perspectives of the children with ASD, I added a neglected voice in the current empirical base on sibling experiences in families of children

with disabilities. Their contribution to this study was invaluable to understanding the depth of the sibling relationships.

As a contribution to the field of developmental science and related disciplines, this study provides is a heightened awareness of not only how ASD can shape sibling relationships (such as level of involvement, interaction style, level of engagement, etc.) but also how these types of relationships could affect the emotional health of the children. Furthermore, this study also highlights how each sibling's individual characteristics bring a certain quality into the relationship. The unique family occurrence of multiple births and ASD has been marginally discussed in the literature. Much of the empirical work has focused on twins relative to the genetics of ASD (Rutter, 2000; Wassink et al, 2004), rather than the relational aspects. The multiple births represented in this study (twins-target family; triplets-focus group) helped to introduce the unique challenges of this special sibling relationship. Identifying these issues allows researchers to begin exploring the distinctive patterns specific to these sibling interactions which can inform family interventions.

Theoretical Framework

The findings support the theoretical context utilized as the framework for this study. Olson's Circumplex Model (Olson, 2000) addresses family nuances and the nature of the relationships within, the family including cohesion, flexibility and communication. Sameroff's Transactional Model (Sameroff, 2009) helps us to understand the mutual impact of ASD in terms of the context of one's environment and the bi-directional/mutually influential interactions that occur within the family.

The three dimensions of the Circumplex Model (flexibility, cohesion, and communication) were supported by the findings in my research.. Olson (2000) describes flexibility as the ability to establish equilibrium and stability when faced with a stressor. The families' ability to integrate the

ASD into their daily lives demonstrated this flexibility. There were varying levels of cohesion or connectedness within each sibling pair, influenced by their adjustment, coping, perspectives, and understanding of ASD. Within the sibling subsystem, the level of cohesion was in struggle between what was desired for the relationship versus what was actually experienced. Yet there was a common thread across all of the pairs for the desire for companionship regardless of the sibling challenges. The communication occurring within each family served as a bridge for the sibling relationships. The level of openness families demonstrated in discussing and educating their children about ASD speaks to the communication dimension of the Circumplex Model. Parents' feedback, modeling, and other means of scaffolding served as an interpretive lens to the sibling interactions and fostered improved dynamics.

The bi-directional and mutually influential interactions that are fundamental to the Transactional Model provides a means to interpret the type of interactions and unique sibling conflict observed with the study families. The individual child characteristics of each sibling as well as the ASD traits influenced the sibling dynamics, often with each child complementing the other. Furthermore, the rejection given by one sibling influenced the response of the other, at times leading to conflict. The type of supports used by the families are relevant examples of the Transactional Model's context of the envirotype (external experiences: cultural, family, and individual code beliefs; values, acceptance, etc.). As Sameroff (2009) notes, the envirotype is made up of various subsystems that transact with the child and the family. These subsystems include the community. While these families drew from the micro and meso levels of their community (Bronfenbrenner & Ceci, 1994), their informal supports were critical. The community's acceptance and value of these F-ASD was significant for the families.

Ethical Considerations and Personal Reflections

As noted by Emerson (1983), qualitative researchers are often presented with ethical issues to consider. Most of the potential dilemmas inherent in this study have already been noted and addressed in earlier sections. However, it is important to summarize these ethical challenges as they were paramount to the appropriate implementation of this study and the overall well-being of the participants. These issues can be classified into three main categories: 1) deceit or lack of full disclosure; 2) covert fieldwork; and 3) researcher-participant relationship/balance of power.

In the discussion of research ethics, the protection of rights of the participants is a priority. Clarifying my role and participant expectations, establishing boundaries around my identity as professional and researcher, and ensuring participant confidentiality address the three main ethical issues of my research. There are five highlighted actions that were implemented to address certain ethical issues that may be specific to this population. First, of particular import, is the sensitive nature of medical and family histories that were shared related to diagnoses and family functioning. One specific step I took to protect this information was to not require families share written evaluations on their child(ren) with ASD (although some form of documentation of the diagnosis was requested). I was sensitive to the fact that in-depth diagnostic evaluations often have family medical and psychological information that families may not have wanted to share for this study. Second, as I engaged in the research endeavor I was mindful of the fact that I could become privy to intervention/support needs of the families, especially of the target families. Although I personally could not provide any direct counsel or intervention, I was able to offer information and resources (via a resource notebook/packet) to all families at the conclusion of their participation in the study. This step helped to address the ethical dilemma of “withholding intervention” when there was an identified or suspected need. This not only allowed me to maintain appropriate boundaries while

undergoing the research, but it also afforded families the opportunity to be informed of specific community supports. Third, for the families that had previous interactions with me as a professional (or may have future interactions with me in the community), I was diligent to inform them that their participation in the study (or lack thereof) would not have any influence on any future professional interactions. I felt this level of transparency was particularly important as the participants evaluated the power within the researcher-participant relationship; and as I evaluated any possible future power dynamics if there were a professional relationship formed (Emerson, 1983; Haggerty, 2004). Fourth, entering into this study, I was prepared to modify or eliminate certain procedures, especially those specifically related to interactions with the child with ASD, if there was any concern about psychological, emotional, or physical harm. I made the choice to eliminate the interview with Blake (TF-ASD) due to his lack of desire to participate. I and his mother made several attempts at easing his comfort with an interview with me or her alone, but after the lack of success, I chose to remove this request because I did not want to cause any discomfort or harm to him. When dealing with vulnerable populations such as children with disabilities, this consideration is of particular import. Finally, as a result of my intimate contact with family interactions, I was aware that I could have been exposed to sensitive topics and interactions; some of which may have required mandated reporting (e.g., child abuse). While this was not an issue in this study, I was prepared to seek counsel from my university advisor and Institutional Review Board, as well as comply with my professional ethical standards of mandating reporting. All families were informed (via the consent form), that I would have been required to report such actions.

Personal Reflections

In qualitative inquiry, the social positioning of the researcher in the process can be rather complicated as a result of her active participation in the research experience. The process of

personal reflection is highly recommended (Becker, 1998) and was practiced throughout the phases of the research. This endeavor helped me to have greater insight into my own biases that I may have inadvertently imposed upon the process (May & Pattillo-McCoy, 2000).

In qualitative research, the investigator is the actual instrument of data collection and the analysis is performed through the subjective eye of the person. Thus, the data are not mediated through impartial means as with quantitative research (Bogdan & Biklen, 1998). I entered into this study as both a student researcher and clinician working with children with ASD and their families. I was aware that this combination provided both a breadth of understanding of the phenomenon, but also a complexity of viewpoint. I was acutely aware that the integrity of the research could be at risk if I did not reflect on these issues. I was aware that my clinical experience could not enter into the research, especially with regards to interpretation of the findings. As such, it was imperative that I acknowledged these concerns and continuously explored my biases and professional-personal experiences with this population and make every attempt to maintain neutrality (Isaac & Michael, 1997).

My professional experience working with the population influenced my approach with the participant families. I was able to adapt my engagement style to their level of functioning and abilities which seemed to help establish rapport with the siblings. There were times during the observations where the children made attempts to engage me out of my “reactive” participant role. My natural inclination was to want to interact with the children; however, I knew I had to maintain appropriate boundaries with the families. I essentially struggled with Daly’s (2007) notion of dynamic objectivity – trying to balance not getting too close, while not seeming too distant. Channeled appropriately, these brief interactions with the children became an asset to the qualitative inquiry.

Drawing on May and Pattillo-McCoy (2000), I recognize that my status as a clinician, specializing in children with disabilities, gave me something of a semi-insider position, affording a level of acceptance and a more open dialogue from parents and siblings that I may not have received otherwise. Recognizing that I am an outsider to the true experiences of these families, I attempted to approach them from a position of humbleness and a desire to learn. I was not in a position to judge them, their experience, or their ability to cope with the situation. Moreover, I wanted the children to feel a sense of authority on this issue of sibling relationships in F-ASD. They were the expert on the topic and it was their story.

During the interpretive phases of the data, I was keenly aware of my clinical background and training in seeing unspoken meanings and identifying underlying causes and connections in behaviors. Nonetheless, I reflected continuously on the fact that my role as a researcher was to observe and listen; not to assess, but describe. I engaged in similar reflection during the interpretation phase of the data analysis. There was a constant self-monitoring of my own analytic behaviors and intentions. I was sensitive to not create themes and patterns that were not concretely (vs. intuitively) evidenced in the data.

Self-reflection is not an event but a process. I am aware that I may come in contact with some of these families in the future in my professional work. I am mindful that, if I have direct interactions with them, they may feel a sense of connection and rapport with me from our interaction through this study and may expect that to transfer over to the professional relationship. Should I have further contact with these families, it will be imperative to uphold my ethical mandates as a researcher while maintaining the friendliness established through the study contact.

Conclusions and Implications for Research, Policy, and Practice

Implications for Research

Ideas for future research have been generated from the themes and other related findings. This study provides further insight into the sibling relationships in F-ASD, and the results suggest additional areas for future research including: 1) sibling relationships across the lifespan, 2) sibling bonding factors, 3) ASD sibling adjustment and coping, 4) cultural contributions to family interactions and perspectives.

Whereas the focus of this study was the sibling relationships in young children, the feedback from the professionals suggest that there is an equal need to consider the role of ASD in family functioning and relationships through the lifespan. Researchers have noted this topic in the literature (Gray, 2002); however, it has been a neglected area of attention in empirical research. The quality of the sibling relationships may change over time as children progress through various developmental milestones (such as the passage from childhood to adulthood, transitioning the adult child to more independence, and the eventual launching of the adult child). Through this life journey, the sibling roles may morph, leading to new interaction dynamics. Research can help reveal other factors that contribute to the sibling trajectory, including parental views on the role siblings play in adulthood (i.e., care giving responsibilities).

To better understand sibling bonding in these families, further research in various areas is needed such as in the bi-directionality of these sibling relationships, individual child characteristics, and the level of knowledge around ASD. From a transactional framework in which family relationships are seen as transactional and bi-directional, we need more research to investigate the influence siblings have on one another, such as how one sibling's contribution and investment to the relationship may influence the other sibling's involvement.

My research demonstrated different types of bonding between the siblings. Now that we have a better understanding how sibling bonding and relationships look in these families, a more in-depth exploration is needed into the factors contributing to the type/level of bonding that occurs in other families as well. The themes from this study suggest that both the individual child characteristics and the knowledge children had about ASD played a part in their sibling bonds. There is scant literature on the education of family members, especially children, about ASD. The type of information received by families may inform how they interpret their family interactions. In addition to this area, more research is needed to explore the connections between individual child characteristics (of each child) as well as potential genetic characteristics to ASD and how these may intersect and impact family members' ability to engage in reciprocal and mutually satisfying ways. For instance, if multiple siblings have ASD or both parent and child has ASD, the quality of their social relationships may be impaired.

Additional studies of F-ASD are needed to help identify the utility of family support services, interventions and programs that might support sibling adjustment. The type of supports needed may be different for specific family members (e.g., mothers, fathers, siblings, grandparents) due to the different stressors, interaction patterns and coping styles. Evident from current research and findings from this study, the severity of a disability may mediate family coping styles and stress (Bouma & Schweitzer, 1990; Noh et al, 1989). Regarding ASD specifically, it has been noted in the literature (Gray, 2002; Kasari & Sigman, 1997; Noh et al, 1989; Stoneman, 2005) that the functioning level of the child and the behavioral manifestations elicit different family/sibling responses, such as the level of stress. The level of functioning in the ASD siblings (i.e., autism vs. Asperger's/HF autism) seemed to be relevant to the differing perspectives and responses to their siblings as evidenced by the focus group and target family sibling feedback. Thus, there is a need

for ASD research that delineates the subtypes of ASD and sibling coping and adjustment. This expanded inquiry must also include the perspectives of the children with ASD.

Much of the ASD literature on child outcomes has been on the effects of the direct intervention work with the child with ASD (Grindle, Kovshoff, Hastings & Remington, 2009; National Institute for Child Health and Human Development, 2001; Solish & Perry, 2008; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). Less has been done to explore and evaluate the effectiveness of family focused interventions on family outcomes. In order to inform ongoing intervention planning and practice, the research community needs to have a greater awareness of the factors that help improve the sibling relationships including those that might involve peer friendships. The peer interactions that occurred during the observations with the Anderson family brought to light the opportunity peers provide. This family's interactions demonstrated the various roles peers can have on sibling interactions such as helping to mediate and serve as a buffer to sibling strain. Through additional research, we may learn how (or if) childhood peers have an influence on sibling perspectives about their sibling relationships. These peers may serve as emotional allies for either the sibling with or without ASD and help interpret miscommunications.

While this study had representation from different racial groups (Caucasian, African American, Armenian-American), this was not a focus of the study. Further investigation into different cultures and socio-economic levels is also needed to better understand family attitudes around ASD. Cultural beliefs may moderate family perspectives on various issues, including ideas regarding birth order responsibilities, roles based on gender and age, views on disabilities, norms around caretaking, and expectations around child behavior and success. Moreover, cultural differences may shape family norms of engagement and perspectives on disabilities including social, communication, and behavioral patterns of interactions (Dyches, Wilder, Sudweeks, Obiakor

& Algozzine, 2004). For example, studies have found that African-American and Latino families report that ASD has less of a negative impact on the family in comparison to Caucasian families (Bishop, Richler, Cain, & Lord, 2007; Blacher & McIntyre, 2006). Relative to socio-economic levels, it is equally imperative to also take a close look at how geographic areas and related resources may impact family education and values around ASD and disabilities (Bromley et al., 2004; Mandell & Salzer, 2007).

Related to ecological issues, there is limited research on families from non-traditional households. Much of the work that has been done has focused on the traditional family unit within a limited socio-economic (SES) level. However, in today's society, the traditional family unit is not necessarily the norm. Less conventional families, such as multigenerational families, grandparents raising grandchildren, and single-parent households also need to be studied as it relates to this topic. These different family compositions may alter how families embrace or reject the diagnosis of ASD and whether they resist or accept informal and formal supports. Hence, there is a need for future research to consider factors such as cultural/ethnic background of the family, habitual coping strategies, socioeconomic status, and community supports and resources. Researchers have found that these factors are linked to family functioning (Keller & Honig, 2004; Peterson & Hawley, 1998).

Finally, replicative studies of my research may provide confirmation and/or provide new revelations to the sibling relationships in these families. A larger sample along with a longitudinal approach may give a more comprehensive look into these families. Because much less is known about ASD and how it shapes sibling relationships, a mixed-methods approach (Creswell, 1999) may help to provide foundational information in this area and may give insight into possible predictive facets of ASD and sibling and family outcomes. The contribution of qualitative and

quantitative methodology can be complementary in various ways such as identifying possible contributing factors to the nature of these sibling relationships, such as gender and birth order. The interactions between the same and different gender siblings in the Johnson family introduce a possible emerging contribution of gender on sibling bonds and relations. Kimberly (ASD-S), Jennifer and Louis (TD-S) jointly identified differences in their interactions as siblings:

Jamell (Ja): ...Is there anything you want to tell me about your brothers?
 Kimberly (K): Me? Well, they're very playable. They are playable. Well, that's pretty much it.
 Ja: So girls, do you think you fight with each other the most?
 Jennifer (Je): Yeah.
 Ja: Do you think that's true Kimberly?
 K: Yeah.
 Ja: So, the sisters fight the most, huh?
 Louis (L): Me and Thomas like each other.
 Ja: You and Thomas like each other?
 L: Yeah.
 K: Thomas is very nicer than Jennifer.

This dialogue points to a gender factor. It is important for future research to explore this possible relationship in more detail.

Implications for Policy and Practice

The findings of this study offer greater awareness of the issues facing siblings in F-ASD and bring forth important implications for practice. From the participant accounts, several areas emerged where professionals can have significant influence in their delivery of services to families. The awareness for practice development includes those related to supports, education, professional training, and community services.

Supports and Education

It is not uncommon for family members to go through the grieving process upon learning of their loved one's disability. Both parents and siblings may experience a sense of loss and must

learn to cope and adjust to their reality: 1) the loss of the child they expected to have or, 2) the loss of the “typical” sibling companion. The support implications begin at this stage. Once parents recover from the shock of the diagnosis, they are often then in need of education around the disability. The personal story from Richard Anderson (TF-P) movingly illustrates the need for education families often have during the early phases of learning of the ASD.

At first, it really frustrated Jane. It was definitely...especially when he was younger it was a struggle just because we didn't know what we were dealing with. We didn't know how to deal with it. I can remember when he was 3/3 ½ /4, it was very difficult sometimes because nothing was making sense. At first, we were trying to figure out, “How come when you tell him ‘no’, he still does it?” Or, “How come he doesn't figure this out?” Once you get to the point where you know there's a reason why and you don't expect him to figure it out, at least you know back off on him. It makes it a little easier.

The perceptions and attitudes around this disorder are shaped by their understanding about ASD. Efforts and funds have been put into the diagnostic and intervention phases of ASD, but less has been done around the education and support of the family after the diagnosis is determined and interventions have started. With adequate support and education around the disability, families can plan for the future, both immediate and long-term, and ensure siblings assume appropriate family roles.

Psycho-education about ASD is paramount for families and the community. Increasing families' support networks is critical to helping them as they move through the phases of coping and acceptance. Many of the parents in this study touched on issues of isolation. Some of the isolation was related to their children's limited social network of friends. For the typically developing sibling, it may have been about embarrassment around their siblings' ASD. Expanding

psycho-education efforts beyond the family unit to the community at large can have a macro impact on reducing the level of isolation many families feel due to the ignorance surrounding ASD. All seven of the professionals noted the need for the children (and their family) to be accepted. One family support worker (P4), stated:

They need to be able to bring peers/friends home that will accept their siblings, naturally.

They need to see people celebrate their brothers or sister's gifts, to be able to know others are also proud of them....

Psycho-education about ASD is paramount for fostering community participation and integration of children with ASD and their families. Increased knowledge and reduced apprehension about ASD has the potential to increase informal (and formal) support services such as respite care; critical in helping to lessen the strain on family relationships. The occasional respite can help ameliorate parental stress and provide the necessary breaks that can help maintain (or create) stronger sibling bonds. As the families shared, these informal support networks are an irreplaceable type of comfort and support in providing temporary relief from caregiver burden and sibling strife.

Parents also discussed a frequent lack of appropriate and available supports that would best meet their children's needs (both for the ASD-S and the TD-S) and validate their experiences. For the Anderson family, especially, outside of the intervention services (i.e., social skills groups) there was little available that was appropriate for their family. There needs to be a greater array of support services for siblings and the children with ASD, across the spectrum of functioning, that can provide validation and normalization of their feelings (e.g., frustration, anger, rejection, pride, etc.) and support. Many of the parents in this study sought out reading material and brief psycho-educational support in their initial quest for education about ASD. However, most had not yet made use of support services for themselves or their children, although they acknowledged a possible

future need. This may suggest that the timing of supports might need to be tiered and provided at various stages of the families' acceptance and understanding of the disorder. It is also important to consider alternate means of providing the services to reduce the strain on the family. With the level of technology available, such options might include phone support, internet chats, or other internet visual/voice communication.

Professional Training and Community Services

In addition to the practice education and support implications discussed, this study has the potential to impact current practice, intervention, and service to children with ASD and their families. Professionals are often the first line of support for families. As such, there is a need for regular in-service training related to ASD of professionals in mental health, case management, education, and advocacy support. Anecdotally, through my experience as a clinician in this field, there is a need for ongoing training so that professionals can have a stronger knowledge base on ASD to better meet the unique needs of these children, their siblings, and parents. The multidisciplinary team working with these families should be included in this process. Training topics are needed in the following areas: 1) sibling relationships in F-ASD and their support needs; 2) treatment needs of children with ASD; 3) information about family support needs; 4) the overall experience of F-ASD; and 4) support needs of the families at different stages of the life cycle.

As professionals reach out to families and their communities, it is critical to consider the impact culture plays in understanding how ASD impacts family relationships. For example, professionals need to be aware of possible cultural differences that may influence the understanding of and response to ASD in the family. Sensitivity around family interpretations of the disability also involves the way in which professionals approach the diagnosis with families. Findings from

this study show that families approach ASD from different perspectives. Hence, it is prudent for professionals to address each family individually; with consideration to their specific interpretation of the meaning to the disorder. This can be as simple as knowing the language used in the family around ASD. As one clinician (P1) noted, “Know the terminology that is used in the family to talk about the disability.” Understanding family perspectives is fundamental to positive family-provider relationships. Furthermore, practitioners need to better understand the decision making process of families to embrace or reject the diagnosis of a disability, including whether they resist or accept informal and formal supports. This understanding can help improve communication between families and providers to expose the potential obstacles and identify ways to breakdown those barriers for families.

Recommendations for practice from practitioners. Understanding the practice needs of these families is best identified and understood directly from those providing the supports. Thus, the feedback from the professional participants in this study is key to understanding the needs of these families. Hence, the professionals’ insights are applied for implications for practice. These specialists in the field of disabilities spoke of similar practice and service needs centered around family education, concrete supports (i.e., respite care and funding), and future planning.

The important contribution typically developing siblings make in these families was mentioned by all of the professionals. One professional (P7) shared, “Siblings have a life- long and ever changing need for information. Siblings’ experience parallels the parents’ experience. The service and consideration siblings get is vis a vis the services and condition parents get.” This profound statement points to a gap in the current services provided to F-ASD. In his comment, this professional noted how the siblings often get shortchanged as direct recipients of education. He

expounded further on the need for greater acknowledgment for the role children, especially the typically developing siblings, play in the life of the family:

There needs to be greater realization that the siblings [of children with disabilities] will be more involved. Support from professionals that profess to be concerned about the family often does not really include siblings. They need to allow siblings [of children with disabilities] to “have a seat at the table.” Professionals need to be made more available for siblings as they are with parents.

Consistent with Furman and Buhrmester’s (1985) research, siblings need to be included in these educational efforts as they will be one of the long-lasting supports for these their brothers and sisters. As it relates to the roles and influence siblings will have long-term, future planning education services are critical practice areas. In some way, the families all touched on future needs their families might have (whether immediate or distant). Research on F-ASD (Gray, 2002) points to the changing needs of the family over time. Parents need support and direction with planning for the well-being of their children (including the TD-S) as they age and may no longer have as prominent a decision-making role for their children. In that vein, as parents age they may need to rely more on the support of the typically developing sibling to be an advocate for the sibling with ASD. As a professional noted (P4), the siblings are concerned about these issues even before being placed in this position, “As kids get older, they might have questions, especially future planning questions.” Diane (FG-P) shared her own personal experience with her son, Charlie (FG-TD), “And, he would worry about them. He’s seven or eight and he’s worried about their future.”

In thinking about the ever changing sibling dynamics, there is a pronounced need for enhanced sibling support services (for both the children with and without ASD) to be included as part of the intervention services for F-ASD. All of the professional participants expressed the

importance for siblings to have a space with others to share their experiences. One of the professionals (P3), an expert on sibling support services, noted:

...I think it's essential that typically developing siblings have the opportunity to share their feelings in a supportive environment with other kids who have a sib with special needs. I think it's critical that kids have the chance to talk with other siblings and realize that they are not alone in the things in which they experience... I think that children are confused about the conflicting feelings they have about their siblings and need to be able to share those feelings and have them validated by others.

Her recommendation holds equally true for the siblings with ASD. They, too, need a space to share their own joys, frustrations, and confusions around their experience. It is critical for children (ASD and TD), when they are young, to have this opportunity to partner with other children. The attitudes they develop as children will likely persist into adulthood when they may need to either assume or accept a greater caretaking role for/by their sibling. As one professional (P7) commented, "Many siblings never had the chance to talk with someone for validation. Often it is not until they are adults when this happens."

Conclusion

The purpose of this dissertation study was to explore sibling relationships in families of children with ASD, considering the contribution of parental assistance and beliefs/attitudes about ASD to these relationships. A secondary goal of this study was to better understand the factors around decisions families make to access sibling support services and how families perceive these services. Despite similarities across families, each family's story was unique and demonstrated the diversity present in ASD, not only with the disorder itself, but also on how it impacts the family via the sibling relationship. The findings of this study point to the fact that there is no one type of sibling relationship in F-ASD. These relationships are bound by the way in which the ASD traits

are seen in each child, the individual characteristics of each child, and the way in which the children (and family) perceive and understand their circumstances. The findings of this study suggest that the disability may be a magnifier of sibling relationships versus a distorter of family functioning. Due to the limited amount of fieldwork and time spent with the families, I cannot formulate a “theory” from this study. However, the attempt is to infer the transfer of concepts from this specific group of families to other families of children with ASD in order to provide a window into the lives of these families.

In conclusion, whereas ASD is a burgeoning topic of research, how it shapes sibling and other family relationships is largely uncharted territory. My research offers a means of exploring and better understanding the complexity in sibling relationships in families of children with ASD. These relationships, at least for the siblings in this study, were quite positive and, in many ways, similar to the relationships between typical siblings. While similar to other sibling relationships, there is the added layer of complexity that the ASD brings to these relationships. The methods employed provided a rich context for capturing the range of experiences of the families. As we learn more about sibling issues and support needs, community and professional services can be enhanced to meet the specific needs of these families. This study can also serve as a launching point for additional research which may aid in strengthening families of children with ASD.

Appendices

Appendix A

Participant Recruitment Information

Advertisement for Participant Recruitment

Families needed for Research on Sibling Relationships in Families of Children with Autism Spectrum Disorders

Siblings in families of children with Autism Spectrum Disorders (ASD) have an opportunity to participate in research aimed at increasing the understanding of sibling relationships in these families. This research has the potential to help improve support services provided to families of children with ASD.

The research is being conducted by Jamell White. She is a student researcher and doctoral candidate at the University of Maryland at College Park. The research will explore the nature of sibling relationships and interactions, while also exploring how parent/adult interactions may contribute to the sibling relationship.

To learn more about this study please e-mail Jamell White at jwhite19@umd.edu or call 240-272-3268. Thank you.

Description of Study

The purpose of this study is to obtain a greater understanding of sibling relationships in families of children with Autism Spectrum Disorders (ASD). The primary focus will be exploring the types of interactions between the siblings. A secondary goal of the study is to understand how parent/adult interactions with the children may contribute to the sibling relationship.

In order to learn more about sibling relationships in families of children with ASD, I will gather information through the following:

- Parent and sibling interviews
- In-home observations of sibling interactions
- Focus Group for Siblings of Children with ASD
- Focus Group for Children with ASD
- Focus Group for Parents of Children with ASD

This is a dissertation study conducted as part of the completion of my doctoral studies at the University of Maryland at College Park. All written information collected as part of this study will be kept confidential. Names and other identifying information that may be broadly discussed in the dissertation paper will be changed in order to protect your family's privacy.

Initial Phone Screening Questions

Parent(s) Name: _____

Name of Child with ASD: _____

Phone Number: _____

Email: _____

Address: _____

1. How were you referred to this study?
2. Has one of your children been diagnosed with an ASD? By whom?
3. If yes, what is the diagnosis?
4. What led you to have your child evaluated?
- 4b. (*If not yet evaluated*) Describe the behaviors that lead you to suspect your child may have an autism spectrum disorder.
5. How would you describe your child's social-communication and verbal skills (child with ASD)?
6. How many other children do you have?
7. What are their ages?
8. Do they have any documented or suspected special needs? Do you have any concerns that may not have been formally evaluated?
9. Are any of your children receiving support services (i.e. individual counseling, group therapy, sibling support services, special education services)?
10. If you are interested in participating in the study, would you be willing to be a target family? (A brief explanation of requirements for target families will be provided—see below).
11. If you are interested in participating in the study, would you be willing to participate in a focus group and/or have your children participate in a sibling focus group? (A brief explanation of requirements for focus group families will be provided—see below).

Explanation of Study:

The purpose of this study is to obtain a greater understanding of sibling relationships in families of children with Autism Spectrum Disorders (ASD), with a focus on the types of interactions between the siblings.

In order to learn more about sibling relationships in families of children with ASD, I will gather information through the following:

Target Families

- Two (2) parent and two (2) sibling interviews (approx. 1 hour each)
- Approximately 3-4 in-home observations of sibling interactions (approx. 1-2 hours each session)

Focus Groups

- One (1), one-hour Focus Group for siblings of children with ASD
- One (1), one-hour Focus Group for children with ASD
- One (1), one-hour Focus Group for parents of children with ASD

This is a dissertation study conducted as part of the completion of my doctoral studies at the University of Maryland at College Park. All written information collected as part of this study will be kept confidential. Names and other identifying information that may be broadly discussed in the dissertation paper will be changed in order to protect your family's privacy.

Appendix B

Questionnaire for Community Professionals

Professional's Name: _____

Type of Community Support Services provided:
(Check all that apply)

- ☐ Individual therapy for children with ASD
- ☐ Individual therapy for siblings of children with ASD
- ☐ Therapeutic groups for children with ASD
- ☐ Therapeutic groups for siblings of children with ASD (including Sibling Support Workshops)
- ☐ Family support services

1. Describe your work with children with disabilities and/or siblings of children with disabilities.

2. What is the average age of the child that comes for these services?

3. On average, how much knowledge do the children have about disabilities and/or ASD?

4. What are some of the issues the children/siblings typically report?

- a. Related to their brother/sister's disability?

b. Related to their typically developing sibling?

c. Are there any unique issues related to ASD?

5. What do siblings generally say about their relationships with their brother/sister with a disability? Their typical sibling?

6. Are there specific support needs that you think children with ASD and/or siblings of children with disabilities/ASD have?

7. Are there any suggestions you might offer to other professionals who work with children with disabilities and/or siblings of children with disabilities?

Appendix C

Letters to Families

Target Family Letter

Dear _____,

Thank you for agreeing to participate in this research project on Sibling Relationships in Families of Children with Autism Spectrum Disorders. I know how generous this is of your time to offer to participate. To the fullest extent possible, I will try to coordinate for the least intrusion possible to your routine.

Over the course of the study, your family will be asked to participate in the following:

- Parent and sibling interviews
- In-home observations of sibling interactions

I will be in touch with you in the next few weeks to schedule a time to come to your home to meet with you and your family. The purpose of this initial home visit is to discuss the specifics of the study and confirm your participation in the study. I am enclosing a description of the study as well as consent forms for your participation. You can feel free to mail the consent forms to me in the enclosed self-addressed stamped envelope prior to the home meeting or wait until the meeting.

Should you decide at this point to decline participation, please contact me as soon as possible. I can be reached at 240-272-3268 (phone) or via email at jwhite19@umd.edu. Thank you again for your interest in this study.

Sincerely,

Jamell White

Dr. Elisa Klein

University of Maryland
Department of Human Development and Quantitative Methodology

Focus Group Letter

Dear Parents,

Thank you for your interest and participation in my research project on *Sibling Relationships in Families of Children with Autism Spectrum Disorders*. I appreciate the time you and/or your child(ren) are giving to this project by participating in focus groups for siblings and/or parents of these siblings.

As you are aware, I am in the process of arranging a time for these groups in the coming weeks. In preparation for your family's participation, there is information that I will need to obtain prior to that date. Your and/or your child's name and any other identifying information will be changed in order to protect confidentiality.

I am attaching the following documents to be signed and returned to me prior to the group meeting:

- Family Screening Form
- Consent Form (one per family)
- HIPAA Form

For the integrity of the research, I am asking for families to provide documentation of your child's diagnosis of ASD (even if that child is not participating in one of the focus groups). Examples of such documentation include: 1) full or partial copy of an IEP; 2) full or partial copy of an evaluation with the diagnosis; 3) copy of a letter from a physician indicating the diagnosis.

In addition to your consent to allow your child(ren) to participate in the sibling focus group(s), I will also obtain his/her assent to participate on the day of the group. I have also attached a copy of the child assent script for your review. Please feel free to review this with your child(ren) before the group.

If you have any questions or would like to speak with me, I can be reached at 240-272-3268 (phone) or via email at jwhite19@umd.edu.

Thank you again for your interest in this study.

Sincerely,

Jamell White

University of Maryland
Department of Human Development and Quantitative Methodology

Appendix D

Family Questionnaire

Note: Only the first names or initials of family members living in the participant family's home (who were not direct study participants) were obtained.

Family Questionnaire

A. DEMOGRAPHIC INFORMATION

Mother's Name: _____ Father's Name: _____
 Address: _____
 Home Phone: _____
 Cell Phone(s): _____
 Work Phone(s): _____
 Emails: _____
 Best time to contact family: _____

1. How would you describe your racial/ethnic background? (Optional)

- ☐ African-American
- ☐ White/Caucasian
- ☐ Hispanic/Latino
- ☐ Mixed
- ☐ Asian or Pacific Islander
- ☐ Other: _____

2. Do you identify with any religion? (Optional) Yes No (circle one)

If yes, which one?

- ☐ Catholic
- ☐ Protestant
- ☐ Jewish
- ☐ Muslim
- ☐ Other: _____

B. PARENT INFORMATION

3. Occupation mother:
 Occupation father:

4. Mother's highest level of education:

GED High School Bachelor's Master's Doctoral

Father's highest level of education:

GED High School Bachelor's Master's Doctoral

5. What would you describe as your household income range? (Optional):

_____ \$0 - \$25,000

_____ \$25,000 - \$50,000

_____ \$50,000 - \$75,000

_____ \$75,000 - \$100,000

_____ \$100,000 – up

6. Parents' current marital status : (circle one)

Single Married Partnered Divorced Separated

7. Are you currently living with a spouse or partner? Yes No

If no, do both parents have joint custody? Yes No

Who has legal custody of the children and/or is the primary caregiver? _____

8. How many adults reside in the home? _____

Please provide first names/initials ONLY and relationship to the family (i.e., mother, father, aunt, grandmother, etc.)

First name _____ Relationship _____

First name _____ Relationship _____

First name _____ Relationship _____

First name _____ Relationship _____

9. Are there other adults that are important to your family and/or spend a significant amount of time with your family/children? (i.e., sitter, neighbor, friend, in-home therapist, etc.)

First name/Initials _____ Relationship _____

First name/Initials _____ Relationship _____

First name/Initials _____ Relationship _____

First name/Initials _____ Relationship _____

10. Which adult does the most childcare with the children? _____

C. CHILD INFORMATION

11. Children's first names ONLY, ages, and gender:

Child with ASD: _____ DOB: _____ Gender: _____

Child 2: _____ DOB: _____ Gender: _____

Child 3: _____ DOB: _____ Gender: _____
Child 4: _____ DOB: _____ Gender: _____

12. Children's Schools and Grade:

Child with ASD:

Child 2:

Child 3:

Child 4:

13. Activities children are involved in (i.e., sports, afterschool activities, clubs, etc.):

Child with ASD:

Child 2:

Child 3:

Child 4:

14. Support services children receive (i.e., individual therapy, speech therapy, etc.):

Child with ASD:

Child 2:

Child 3:

Child 4:

15. Do you suspect any special needs with any of your other children?

Child 2:

Child 3:

Child 4:

Appendix E

Child Assent Script

Hi, my name is Jamell White. I am doing a project for the University of Maryland to learn about brothers and sisters and how they spend time together. I would like to come to your home and watch how you spend time with your brother/sister. I would also like to ask you some questions about you and your brother/sister. If you want, you can be in my study.

Besides your family, other people will not know if you are in project. I will put things I learn about you together with things I learn about other children, so no one can tell what things came from you. When I tell other people about my research project, I will not use your name, so no one can tell who I am talking about.

Your parent(s) have to say it's OK for you to be in the study. After they decide, you get to choose if you want to do it too. It is OK if you do not want to do these activities; no one will be mad at you. If you say yes and then change your mind later, that's OK. You can stop at any time. You can stop talking to me and/or ask me to stop coming to your home to watch and learn about how you spend time with your brother/sister.

Do you have any questions? Is it OK for me to come to your home, talk with you, and learn more about you and your brother/sister?

I will give you a copy of this form in case you want to read it again later with your parent(s). Your parent(s) have my phone number in case you have any questions and want to call me or if you decide you don't want to be in the study any more.

Appendix F

Target Family Interview Questions

Individual Interview Questions—Typically Developing Siblings

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

1. Tell me about your family.
2. How many siblings do you have?
3. How old are your siblings? Are you the oldest, youngest, or middle child?
4. Do you have a brother/sister with ASD?
5. What do you know about ASD?
6. Describe your brother/sister with ASD?
7. What do you like to do with your sibling(s)? How often do you do this with him/her?
8. Is there anything you wish you did more with your brother/sister?
9. If you needed help playing with your brother/sister at home, who would you go to? Why would you ask that person to help you?
10. Do you ever have arguments/fights with your brother/sister? What are the arguments usually about?
11. What do you like about your brother/sister?
12. Sometimes kids with ASD can get really upset and frustrated about things that don't seem to make sense to us. Does that happen with your brother/sister? Tell me about it? What do you do when that happens?
13. Some kids with ASD only like to play certain games and play them only a certain way. Is your brother/sister like that? Tell me about it.
14. If I asked your brother/sister with ASD to describe you, what do you think he/she would say?
15. What is the hardest thing about having a brother/sister with ASD? Is there anything you like about having brother/sister with ASD?
16. If you could change anything about your brother/sister, what would you change?
17. Do your friends know about your sibling's challenges?
18. Do friends come over to your house to play?
19. What activities do you do as a family?
20. What is your favorite thing to do with your family?
21. Do you go to the same school as your brother/sister with ASD? What is that like?
22. What do you think I should know about you and your brother/sister with ASD?

Individual Interview Questions—Siblings with ASD

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

1. Tell me about your family.
2. How many siblings do you have?
3. How old are your siblings? Are you the oldest, youngest, or middle child?
4. Do you like having brothers/sisters?
5. What do you like to do with your sibling(s)?
6. Is there anyone in your family who helps you to play with your brother/sister? Who is that? How do they help you?
7. If your brother/sister wanted to play or do something with you that you didn't want to play, what would you do?
8. Is there anything you wish you did more with your brother/sister?
9. Do you ever have arguments/fights with your brother/sister? What are the arguments usually about?
10. What do you like about your brother/sister?
11. How would you describe your brother/sister?
12. If I asked your brother/sister to describe you, what do you think he/she would say?
13. What are some things you are good at? What are some things you have a hard time with?
14. What activities do you do as a family?
15. What is your favorite thing to do with your family?
16. Do you go to the same school as your brother/sister? What is that like?
17. What do you think I should know about you and your brother/sister?

Parent Interview Questions

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

Family Information

1. Tell me a little about your child with ASD, your other children, and the family as a whole.
 1. When was your child diagnosed?
 2. What was your initial reaction to the diagnosis? Your family's?
 3. What were some of the issues you and your family have had to deal with related to this diagnosis?
2. Regarding your child with ASD, what specific diagnosis was he/she given?
3. Tell me what you know about ASD.
4. When you were first introduced to the possibility that your child had ASD, what type of information did you seek out?
5. What does having a child with ASD mean to you? What does it mean to you as a family?
6. What helped you and your family most during that time when you first found out about the diagnosis?
 1. What was not helpful to you during that time?
 2. How are you feeling about things now?
7. How would you describe your family interaction style and overall relationship?
8. Describe a typical day for your family.
9. What are some of the things you like to do together as a family?
10. Has this diagnosis changed your "family life" or way of doing things?
11. What kinds of activities are you involved in for leisure? Your children? Your spouse/partner?
12. What are some of the things that you (the parent) like to do with your children/each child/etc.?
13. How would you describe your relationship with your child with ASD? Your other children? How would you describe your spouse's/partner's relationship with the children?
14. What are some of the challenges of having a child with ASD?
15. What are some of the positives of having a child with ASD?
16. How has all of this been for you and your spouse/partner as a couple?
17. Tell me about your experience as a parent and couple caring for a child with ASD.

Sibling issues

1. How has it been for your other children having a sibling with ASD?
2. What do your children know about ASD in general?

3. Do your children know about your child's diagnosis (including the child with ASD)?
4. How did you tell them about the diagnosis? Do you remember how you explained it to them? What did you say?
5. How would you describe your children's relationships with one another?
6. What are some of the things your children like to do together?
7. Do you think your child's disability shapes how he/she engages with the family?

Support needs

1. What types of supports are you currently receiving/received in the past?
2. Are you on the waitlist for any services?
3. Are/were there any specific services that you found particularly helpful to you (as a parent) or your children?
4. Are there any types of support that you wish would have been or could be available to you and your children?
5. What types of support are/were least helpful to you?
6. Are there any suggestions you might offer to professionals who work with children with ASD and their siblings/parents?
7. Are there any sibling support needs (both for the child with and without ASD) that you would like professionals to know about?
8. Are any of your children involved in any support services related to the ASD (i.e., sibling support services, individual counseling, group therapy)

Appendix G

Focus Group Interview Questions and Sample Activities

Typically Developing Siblings

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

The researcher gave a brief introduction and had each participant briefly tell his name, his siblings' names and one thing about himself.

1. How many siblings do you have?
2. How old are your siblings? Are you the oldest, youngest, or middle child?
3. Do you have a brother/sister with ASD?
4. What do you know about ASD?
5. Do you ever have arguments/fights with your brother/sister? What are the arguments usually about?
6. What do you like about your brother/sister?
7. What is the hardest thing about having a brother/sister with ASD? Is there anything you like about having brother/sister with ASD?
8. If you could change anything about your brother/sister, what would you change?
9. Do your friends know about your sibling's challenges?
10. Do friends come over to your house to play?
11. What activities do you do as a family?

Sample Activities for Sibling Focus Groups

The purpose of these types of experiential/interactive activities is to encourage thought and elicit feedback related to the experience of being a sibling of a child with ASD and/or being a child with ASD.

Sample Activity 1:

Draw a picture of your family. In your picture, you and your family can be doing anything you want.

(After the picture is completed) Tell us about your picture. What is your family doing in this picture? Why did you decide to draw this picture?

Sample Activity 2:

Think of each member of your family (including yourself). If you could pick an animal that describes each person of your family, what animals would they be? For example, when I think of

my mother, I think of an owl because my mother is very smart and wise. When I think of my older sister, I think of a _____ because_____.

I may allow the children to draw pictures of these animals or just talk about it. As the children describe the animals/family, I may ask: How do these animals get along with each other?

Sample Activity 3:

(For older elementary school/early middle school-aged children)

Children will be given a pre-cut piece of paper that is in the shape of a house. The children will be given a brief introduction to the activity.

Introduction: Sometimes people can wear pretend masks that show (on the outside) how they want people to see them. But on the inside, they feel very different. For example, if I'm sad because I got a bad grade, I might still put a smile on my face, even though inside I feel like crying. Also, sometimes we show people only the things we want them to see, and keep some things private. For example, I might have a very messy bedroom. But when I invite a friend to my house, I clean my room really well. So, when my friend comes over to my house, she might think that my room is always clean. But in reality, most of the time my room is messy. Or, sometimes we have to behave in different ways depending on where we are. For example, when you are in the library, you have to speak softly and not run around. But, when you are outside on the playground you can talk loudly, laugh, and run around. It all depends on where you are.

The children will be asked to draw a picture (using the house cut-out) of how: 1) they believe people see their family from the outside (on the front side of the house). *"If/When your friends think about or describe your family, what do you think they would say? How do they believe you are together?"*; and 2) what their family is really like on the inside (on the back side of the house). *"How are you and your family when you are home alone and friends aren't around? Do you think what your friends see on the outside is the same as what really happens on the inside?"* The children will be given a chance to discuss their pictures.

Sample Activity 4:

In this experiential activity, I would allow each child to experience what it is like to have a disability.

Examples of disabilities:

Learning disability: children will be asked to complete a simple writing task such as writing their name and address using their non-dominant hand

Physical disability: children will be asked to wear a sling on their dominant hand and complete a task such as making a block structure

ASD/sensory issues: children will be asked to answer simple questions (for example "Where do you live?" and "What is your phone number?") while listening to music on an iPod).

Each child would have a different "disability" and would participate in a group activity while having the disability. We would then discuss how it felt to have a disability. I would then ask them what they think their brother or sister experiences based on their ASD.

Parent Focus Group Questions

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

The researcher gave a brief introduction and had each participant briefly tell his/her name, children's ages and one sentence about his/her child with ASD.

Family Information

1. When was your child diagnosed?
2. What was your initial reaction to the diagnosis? Your family's?
3. What were some of the issues you and your family have had to deal with related to this diagnosis?
4. When you were first introduced to the possibility that your child had ASD, what type of information did you seek out?
5. How would you describe your family interaction style and overall relationship?
6. What are some of the things you like to do together as a family?
7. What are some of the challenges of having a child with ASD?
8. What are some of the positives of having a child with ASD?
9. How has all of this been for you and your spouse/partner as a couple?

Sibling issues

8. What do your children know about ASD in general?
9. Do your children know about your child's diagnosis (including the child with ASD)?
10. How would you describe your children's relationships with one another?
11. How do you think your child's disability shapes how he/she engages with the family?

Support needs

9. What types of supports are you currently receiving/received in the past?
10. Are you on the waitlist for any services?
11. Are/were there any specific services that you found particularly helpful to you (as a parent) or your children?
12. Are there any suggestions you might offer to professionals who work with children with ASD and their siblings/parents?

Focus Group Questions and Sample Activities—Siblings with ASD

Note: These open-ended questions were intended to guide the interview process. Additional questions may have been asked as the interview progressed. Not all questions were necessarily asked and interviewees were not required to answer any specific question.

The researcher will give a brief introduction and have each participant briefly tell their names, their siblings' names and one thing about themselves.

18. How many siblings do you have?
19. How old are your siblings? Are you the oldest, youngest, or middle child?
20. Do you like having brothers/sisters?
21. Is there anything you wish you did more with your brother/sister?
22. What do you like about your brother/sister?
23. How would you describe your brother/sister?
24. If I asked your brother/sister to describe you, what do you think he/she would say?
25. What is your favorite thing to do with your family?

Sample Activities for Sibling Focus Groups

(These activities may also be used during individual sibling interviews)

The purpose of these types of experiential/interactive activities is to encourage thought and elicit feedback related to the experience of being a sibling of a child with ASD and/or being a child with ASD.

Sample Activity 1:

Draw a picture of your family. In your picture, you and your family can be doing anything you want.

(After the picture is completed) Tell us about your picture. What is your family doing in this picture? Why did you decide to draw this picture?

Sample Activity 2:

Think of each member of your family (including yourself). If you could pick an animal that describes each person of your family, what animals would they be? For example, when I think of my mother, I think of an owl because my mother is very smart and wise. When I think of my older sister, I think of a _____ because _____.

I may allow the children to draw pictures of these animals or just talk about it. As the children describe the animals/family, I may ask: How do these animals get along with each other?

Sample Activity 3:

The children will be encouraged to make paper bag puppets (one of themselves and one of their sibling). Using the puppets, the children will role play an interaction between the sibling puppets. During the activity, they will be asked to describe their puppets and why they colored them as they did. During/after the role play, the children will be asked to explain why they chose the role play scenario.

Sample Activity 4:

Using paper scenes, children will be able to pick a scene and use the paper dolls (of various men, women, children) to create a pretend family scene.

Examples of paper scenes:

- Living room background
- Bedroom background
- Kitchen background
- School background
- Playground background

Level of involvement	Sibling interaction style	Sibling interaction activities	Parental assistance with sibling interactions	Family interaction activities	Sibling bonds	Sibling Adjustment/ Coping	Sibling education about ASD	Community resources and support	Family Stress
Engaged	Cooperative interaction	Interactive activity	p.playmate	Split family activities	Caring	Embarrassment	Parent-guided education about ASD	Respite care	Confusion about circumstance
Disengaged	Strained interaction	Passive activity	p.feedback	Joint family activities	Connected	Acceptance		Funding	
Rejection of Sibling interaction/ Non-responsive	Parent-guided interaction		p.scaffolding	Modified family activities	Disconnected	Frustration	Professional-guided education about ASD	Future planning	Family member strained interactions
	Brief/fleeting interaction			Family life as usual	Adversarial	Pride	ASD Sibling-guided education	Informal Community supports	
	Continuous interaction				Mixed bondedness	Ambivalence		Understanding and support of family values/beliefs	
	Passive-Aggressive					Grief			
	TD sib led					Isolation			
	ASD sib led					Sadness			
	Parallel play					Jealousy		Community Education	
	Similar to TD/TD sibs					Loneliness			
	Reverse birth order					Confusion re: circumstances			
	Accommodating								

Appendix I

Co-occurring Codes

	ASD charac	ASD commun ability	Beliefs re: ASD	Common btw sibs	Commun Res	Fam inter act	Family stress	Indiv child charac	Knowledge re: ASD	Level of Invol	Mental hlth support	Parent assist w/ sib interac	Severity of ASD	Sib adjust/coping	Sib Bonds	Sib conflict	Sib ed re: ASD	Sib interac act	Sib interac style	Sib Roles
ASD characteristics		5-0.02	1-0	2-0.01	1-0	6-0.03	2-0.01	15-0.06	4-0.02	18-0.07	4-0.02	8-0.03	1-0	24-0.09	5-0.02	8-0.03	1-0	n/a	19-0.06	3-0.01
ASD communication ability	5-0.02		1-0.03	1-0.02	n/a	1-0.02	n/a	1-0.01	1-0.02	1-0.01	n/a	4-0.05	1-0.04	1-0.01	1-0.01	n/a	n/a	n/a	3-0.02	n/a
Beliefs/Attitudes about ASD	1-0	1-0.03		1-0.02	3-0.05	1-0.01	2-0.04	1-0.01	9-0.17	n/a	1-0.02	n/a	n/a	5-0.04	1-0.01	n/a	5-0.11	n/a	1-0.01	n/a
Commonalities between siblings	2-0.01	1-0.02	1-0.02		n/a	3-0.04	n/a	1-0.01	n/a	7-0.06	n/a	n/a	1-0.02	4-0.03	3-0.03	1-0.01	n/a	n/a	7-0.04	n/a
Community resources and supports	1-0	n/a	3-0.05	n/a		1-0.01	n/a	2-0.02	n/a	n/a	1-0.01	n/a	n/a	1-0.01	1-0.01	n/a	n/a	n/a	1-0.01	3-0.03
Family interaction activities	6-0.03	1-0.02	1-0.01	3-0.04	1-0.01		1-0.01	2-0.02	n/a	8-0.06	3-0.04	n/a	1-0.02	7-0.05	4-0.03	1-0.01	2-0.03	n/a	4-0.02	2-0.02
Family stress	2-0.01	n/a	2-0.04	n/a	n/a	1-0.01		n/a	2-0.04	1-0.01	1-0.02	n/a	n/a	16-0.16	4-0.04	n/a	1-0.02	n/a	n/a	n/a
Individual child characteristics	15-0.06	1-0.01	1-0.01	1-0.01	2-0.02	2-0.02	n/a		n/a	6-0.03	2-0.02	5-0.03	n/a	4-0.02	5-0.03	5-0.04	n/a	2-0.02	11-0.05	3-0.02
Knowledge about ASD	4-0.02	1-0.02	9-0.17	n/a	n/a	n/a	2-0.04	n/a		n/a	n/a	1-0.01	2-0.04	4-0.03	n/a	2-0.02	7-0.13	n/a	1-0.01	3-0.04
Level of Involvement	18-0.07	1-0.01	n/a	7-0.06	n/a	8-0.06	1-0.01	6-0.03	n/a		n/a	1-0.01	n/a	7-0.04	10-0.06	5-0.04	1-0.01	5-0.05	34-0.17	5-0.04
Mental health supports	4-0.02	n/a	1-0.02	n/a	1-0.01	3-0.04	1-0.02	2-0.02	n/a	n/a		n/a	1-0.02	3-0.02	3-0.03	n/a	2-0.04	n/a	1-0.01	n/a
Parental assistance with sibling interaction	8-0.03	4-0.05	n/a	n/a	n/a	n/a	n/a	5-0.03	1-0.01	1-0.01	n/a		n/a	3-0.02	1-0.01	4-0.03	2-0.02	n/a	9-0.04	4-0.03
Severity of ASD	1-0	1-0.04	n/a	1-0.02	n/a	1-0.02	n/a	n/a	2-0.04	n/a	1-0.02	n/a		1-0.01	n/a	n/a	n/a	n/a	n/a	n/a
Sibling adjustment/coping	24-0.09	1-0.01	5-0.04	4-0.03	1-0.01	7-0.05	16-0.16	4-0.02	4-0.03	7-0.04	3-0.02	3-0.02	1-0.01		16-0.11	8-0.06	3-0.03	n/a	12-0.05	7-0.05
Sibling Bonds	5-0.02	1-0.01	1-0.01	3-0.03	1-0.01	4-0.03	4-0.04	5-0.03	n/a	10-0.06	3-0.03	1-0.01	n/a	16-0.11		6-0.05	1-0.01	1-0.01	9-0.04	10-0.09
Sibling conflict	8-0.03	n/a	n/a	1-0.01	n/a	1-0.01	n/a	5-0.04	2-0.02	5-0.04	n/a	4-0.03	n/a	8-0.06	6-0.05		1-0.01	n/a	12-0.07	2-0.02
Sibling education about ASD	1-0	n/a	5-0.11	n/a	n/a	2-0.03	1-0.02	n/a	7-0.13	1-0.01	2-0.04	2-0.02	n/a	3-0.03	1-0.01	1-0.01		n/a	1-0.01	1-0.01
Sibling interaction activities	1-0	n/a	n/a	n/a	n/a	n/a	n/a	2-0.02	n/a	5-0.05	n/a	n/a	n/a	n/a	1-0.01	n/a	n/a		2-0.01	2-0.03
Sibling interaction style	19-0.06	1-0.02	1-0.01	7-0.04	1-0.01	4-0.02	n/a	11-0.05	1-0.01	34-0.17	1-0.01	9-0.04	n/a	12-0.05	9-0.04	12-0.07	1-0.01	2-0.01		7-0.04
Sibling Roles	3-0.01	n/a	n/a	n/a	3-0.03	2-0.02	n/a	3-0.02	3-0.04	5-0.04	n/a	4-0.03	n/a	7-0.05	10-0.09	2-0.02	1-0.01	2-0.03	7-0.04	

Note: co-occurrence frequency numbers (number of co-occurrence events) and c-coefficients(strength of the relation between items) are listed. The darker color, the stronger the relation.

Glossary

ASD:	Autism Spectrum Disorder
ASD-S:	Sibling with ASD
DS:	Down Syndrome
FG:	Focus group participants
EE:	Expressed emotion
F-ASD:	Families of children with Autism Spectrum Disorders
FG-P:	Focus group parent(s)
FG-TD:	Focus group typically developing sibling
ID:	Intellectual disability
PDD NOS:	Pervasive Developmental Disorder, Not Otherwise Specified
SIBS-ASD:	Siblings of children with ASD (literature review only)
SIBS-DD:	Siblings of children with disabilities (literature review only)
SIBS-TD:	Siblings of typically developing children (literature review only)
TF:	Target family participants
TF-ASD:	Target family child/sibling with ASD
TF-P:	Target family parent
TD-S:	Typically developing sibling
TF-TD:	Target family typically developing child/sibling
ToM:	Theory of Mind

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